DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT, 1981

HEARING

BEFORE THE

SUBCOMMITTEE ON THE HANDICAPPED

OF THE

COMMITTEE ON LABOR AND HUMAN RESOURCES UNITED STATES SENATE

NINETY-SEVENTH CONGRESS

FIRST SESSION

ON

EXAMINATION OF THE IMPLEMENTATION OF THE DEVELOPMENTAL DISABILITIES BILL OF RIGHTS ACT

APRIL 30, 1981

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DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT, 1981

THURSDAY, APRIL 30, 1981

U.S. SENATE,
SUBCOMMITTEE ON THE HANDICAPPED,
COMMITTEE ON LABOR AND HUMAN RESOURCES,
Washington, D.C.

The subcommittee met, pursuant to notice, at 9:35 a.m., in room 4232, Dirksen Senate Office Building, Senator Lowell Weicker (chairman of the subcommittee) presiding.

Present: Senators Weicker, Randolph, Nickles, and Stafford.

Staff present: John A. Doyle, subcommittee staff director, and Michael Morris, Frank J. Kinney III, and Judi Buckawa, professional staff members.

OPENING STATEMENT OF SENATOR WEICKER

Senator WEICKER. Today's hearing will cover some familiar ground. For more than a decade, Congress has recognized the need to help States deliver services to people with developmental disabilities.

The wording of section 6010 of the Developmental Disabilities Act deliberately sets standards for State care. It stipulates the right of every disabled person to habilitative care that restricts that person's personal liberty as little as possible.

In times of fiscal austerity, we must not yield to the temptation to place a price tag on our highest human values. If we believe in human rights and dignity, if we believe in maximizing the potential of every individual, we must be willing to foot the bill for what we believe in. That is not to say that we should throw dollars at disabilities. Rather, State and Federal funds must be targeted and invested in a way that will make disabled individuals more productive members of our society. Such investments will reap many dividends in the long run.

Federal policy in funding must, for the severely disabled child born today, build a stronger support system to help to keep that child's family together. It must promote attitudes and environments accepting of disabled people so that they may live and learn with their peers in our neighborhoods and schools. And by the time that disabled child reaches adulthood, together we will have built a new tradition of dignity and opportunity for all people, regardless of their abilities or disabilities.

Keeping in mind that the United Nations has designated 1981 the International Year of Disabled Persons, it is my hope that today's hearing will focus on opportunities brought about by the

Developmental Disabilities Assistance and Bill of Rights Act, that will identify unmet needs and result in recommendations for further improvement.

I notice that Senator Nickles has just come into the room.

Senator, do you have an opening statement you would care to make at this point?

Senator NICKLES. Yes, I do.

Senator WEICKER. Go right ahead.

Senator NICKLES. Good morning, Mr. Chairman. I am sorry I am a couple of minutes late.

I appreciate the opportunity to be here, and I wish to congratulate you for holding these hearings on what I think is a most important subject.

I think it is important to have oversight hearings on developmental disabilities and rehabilitative services. Your particular record of leadership in recognizing the needs and difficulties facing the severely handicapped has certainly been an example and a challenge to myself and to our colleagues. For this reason, I look very much forward to working with you on this subcommittee.

The proposal to include developmental disabilities and rehabilitative services in the social services block grant has probably been the most effective catalyst for drawing out the very basic and critical questions concerning the entire block-grant concept. Not one of us can look at those who are severely disabled and not recognize that we have a special responsibility to protect and assist these Americans. They are, if you will excuse the already overused expression, "the truly needy".

Knowing this, we all look with concern at the proposal to place their programs into the common pot. The most basic challenges to the block-grant concept are drawn out, as we wonder if the developmentally disabled can somehow get lost in the competition with all 46 goods and services, or will be so underserved from severe cuts that we will be a step back from what may indeed have been the dark ages for this particular group.

I have certainly asked and been asked these kinds of questions, and the answers really do not come very easy. However, as I have studied the President's proposals, particularly in light of the handicapped, I have found reasons for hope and not for despair.

I do not believe that we can move back as a nation to the age of unawareness of the needs of the handicapped. I can say this because I believe that the problems of the past grew first from the simple lack of true understanding of the day-to-day situations facing severely handicapped people and not out of disregard. We have come too far as a nation to turn our backs on the most needy. I find the notion that State legislators, Governors and State department heads are somehow more likely to be more politically corrupt than this esteemed body of Congress to be most ridiculous. Fortunately or unfortunately, depending on your perspective, we all have no choice but to share in human nature. Too many people in government, in the home, and in the community have been touched in a permanent way in the last 10 years to turn their backs on the efforts for the handicapped now.

I am also inclined to believe that the block grants will allow a true coordination of services so that, for example, a handicapped

child who has been an abused child and is currently a foster child will receive more comprehensive assistance in a much simpler and more coordinated fashion. Less agency shuffling of forms would indeed be an improvement.

While the new and different always required transition, it is most important to relinquish some of the reins of control, I am inclined to believe that when scrutinized under the penetrating light of its effect on the handicapped, the President's proposal represents not a turning of our backs, but an effort to improve the delivery of assistance to the handicapped of this country.

I look forward to hearing from our witnesses today and exploring the concerns and questions of them and also of yourself, Mr. Chairman, and other members of this committee.

Thank you very much.

Senator WEICKER. Thank you very much, Senator Nickles.

We have with us our distinguished colleague, the chairman of this subcommittee for many years. I am perfectly willing to even designate him as, in spirit, still the chairman. There are a few procedures that stand in the way of giving you the official title, but otherwise, you certainly, in terms of recognition, deserve it.

Senator Randolph.

Senator RANDOLPH. You are very thoughtful and too generous, Mr. Chairman. I am delighted to join with you in the continuing effort to bring about equity for the handicapped. I am delighted to know that Senator Nickles and many others within the committee and subcommittee structure will, under your leadership, continue to strengthen these efforts.

I do not do this in a cursory way, but I do it because I want to and believe it is merited. I want to indicate that for a long time, the able Senator from Connecticut, Lowell Weicker, as he moves into a decisionmaking position as the chairman of the subcommittee, has a record that will stand us all in good stead.

I am pleased to welcome our witnesses today and to express my appreciation for their willingness to participate in this hearing and provide the Subcommittee on the Handicapped with the benefit of their knowledege and experience on the Developmental Disabilities Assistance and Bill of Rights Act.

The Developmental Disabilities Assistance and Bill of Rights Act is targeted on this Nation's nost vulnerable population—those severely handicapped persons whose disability orginated prior to age 22 and therefore impacted on the developmental progress of that individual.

As you all know, the implementation of this act has not been without difficulty, as the GAO report indicated last year. It has always been my belief, however, that criticism should be reviewed carefully and then used constructively to improve the implementation of the program.

It is my firm conviction that handicapped citizens have a great deal to offer this country, and I have endeavored over the years to work to enhace their opportunities to become participating and contributing members of society. As discussions of the administration's block grant proposals proceed, I will continue to do my part to maintain a strong programmatic focus on the needs of handicapped persons. I an greatly concerned that the needs of handi-

capped Americans will be overlooked if programs for the handicapped are block granted with other programs.

Thank you very much.

Senator WEICKER. Thank you very much, Senator Randolph.

I want to make clear at the outset that this is not a hearing to approve the administration's proposal, and neither to necessarily disapprove; rather, just as you state, to review. Indeed, the Chair would state—not speaking for any Senator—but the Chair would state that I have to be convinced that the block grant approach is the approach to take, and that, of course, is the purpose of these hearings, that we have all these matters laid before us and justified.

I am not, like too many of my colleagues, on the matter of the budget willing to accept these matters on faith. I am only willing to go ahead and be convinced with a preponderance of the evidence.

Senator Kennedy has sent word to the committee that he is delayed at a White House ceremony on the Holocaust. He expresses his regrets at not attending, but wants the record to show both his and his family's special support and interest for the DD program. His remarks on this will be included in the record at this point when given to the committee.

[The prepared statement of Senator Kennedy follows:]

PREPARED STATEMENT OF SENATOR KENNEDY

Senator KENNEDY. I want to commend the chairman of the subcommittee, Senator Lowell Weicker, Jr., for his continuing leadership in pursuing expanded opportunities for handicapped Americans. Over the course of recent years, I have been pleased to work with him on issues affecting mentally retarded and physicially handicapped people. His continuing concern and commitment are important factors in the progression of legislation designed to meet the needs of these millions of Americans.

Our hearing today is one further step that began in 1963 when President Kennedy initiated the first mental health and mental retardation legislation.

He said then that the nonsystem of mental health and mental retardation services "Has been tolerated too long. It has troubled our national conscience, but only as a problem unpleasant to mention, easy to postpone and despairing of solution."

In the years since, we have achieved significant gains, mental health care and services for developmental disabled people shifted from vast institutions where people were confined—and all too often condemned to permanent isolation—to community settings where the fundamental goal is to permit every individual to achieve the maximum development of his or her talents and potential.

Community mental health centers and group homes for mentally retarded people are in operation and provide vital services. Professionals able to meet the needs of the mentally ill and developmentally disabled have more than doubled. And in the Developmental Disabilities Assistance and Bill of Rights Act, we took a major step to give substance to the national policy of deinstitutionalization.

It was a determination to move beyond mortar and bricks to enact a Federal-State partnership aimed at comprehensive serivces for the 3 million developmentally disabled citizens in this land.

It was more than a bill authorizing specific dollars for specific services. It was a national statement of commitment to the rights of developmentally disabled people. It was a national declaration that we would not tolerate anywhere in this land the existence of institutional warehouses where human beings are shut away forever.

The recent Supreme Court decision spotlights again the complexity of this issue. But we cannot retreat from our commitment to deinstitutionalization. We must recognize the difficulty in achieving the national transition from institutional care to community-based settings; but we must insure that the Bill of Rights has meaning for the lives of people with developmental disabilities.

The right to become a contributor to our society cannot be denied by administrative foot-dragging while human beings remain at physical and psychological risk.

The Supreme Court decision makes these hearings of enormous importance not merely to the current bill we are considering but to the entire thrust of National policy over the past 18 years.

We must insure that this legislation reiterates in specific, clear and compelling terms the means by which the principles of equity and equal opportunity are to be insured to the developmentally disabled.

The Federal Government must continue to plan, coordinate, monitor and provide research and training to assist developmentally disabled people.

The heart of the developmental disabilities program has been the State planning councils and the crucial services provided in designated priority areas within each State.

Funded by State formula grants, these councils have identified needs, coordinated comprehensive services, and monitored the quality of those services.

They have relied not only on representatives of agencies engaged in offering services but insured at least half of the council members are disabled individuals and their relatives. The councils have become town meeting halls for the recipients themselves to express concerns, to advocate program improvements, and to pursue new solutions to their problems. And they must be continued.

The developmental disabilities program also supports the 36 university affiliated facilities which constitute the sole comprehensive training program in the field of mental retardation and developmental disabilities. Each year UAF's train 140,000 students, professionals, paraprofessionals, and parents through course work, inservice training and special seminars.

UAF's also provide direct services to more than 68,000 developmentally disabled persons. Many of those individuals rely entirely on the UAF's because they are the only source of integrated service providers able to deal with the complexity of those individuals' needs.

The underlying UAF philosophy is to meet the needs of handicapped persons as well as their families. That is the philosophy

that the Developmental Disabilities Act has fostered and it is the philosopy that we must maintain.

It has enabled families to remain together and it has prevented the multiple costs of institutionalization, costs in dollars and costs in human misery.

Finally, the UAF's have been our vanguard in the research battle, pressing scientific inquiry to discover the PKU screening method and fetal alcohol sydrome. Those discoveries have significantly reduced the incidence of mental retardation.

The UAF's must continue to receive our full and unrestricted support.

I am sure that the witnesses today will provide us with new information and new insights in how to maintain our national goals of securing a future of hope and opportunity for people with developmental disabilities.

Senator WEICKER. Our first witness is Teresa Hawkes, Acting Director of the Office of Program Coordinatior and Review of the Office of Human Development Services.

Ms. Hawkes, please proceed with your testimony.

STATEMENT OF TERESA HAWKES, ACTING DIRECTOR, OFFICE OF PROGRAM COORDINATION AND REVIEW, OFFICE OF HUMAN DEVELOPMENT SERVICES, DEPARTMENT OF HEALTH AND HUMAN SERVICES, ACCOMPANIED BY FRANCIS LYNCH, ACTING COMMISSIONER, ADMINISTRATION FOR DEVELOPMENTAL DISABILITIES

Ms. HAWKES. Thank you.

I want to introduce Francis Lynch, the Acting Commissioner of the Administration for Developmental Disabilities, who is with me today.

Senator WEICKER. Nice to have you.

Ms. HAWKES. I want to thank vou for this opportunity to appear here today to give you an overview of the administration proposal to create a social services block grant.

I have a brief overview statement, and would be pleased to then answer any questions that you would have.

The social services block grant proposal is a part of the larger program the President has outlined—a package of initiatives designed to restore the health and vigor of the national economy. The most important thing that we can do, not only for the groups we are concerned about in the social service programs, but for all citizens, is to put the Nation's economy on a sound footing and reduce the inflation that makes economic self-sufficiency so difficult for so many people.

At the same time, this administration retains a strong commitment to provide assistance to those most-in-need members of society, who without that support would lack the most basic necessities of life.

However, we believe that the present categorical program structure is cumbersome and inefficient. Resources that should be used for services are being used for meeting multiple and often conflicting Federal administrative requirements. The differences in eligibility make it difficult for service programs to meet multiple needs of clients, or to refer them from one program to another. States do

not have the flexibility they need to target resources on problems which they regard as most important.

For these reasons, we have chosen the social services block grant approach to address social services. The approach is designed to eliminate the burdensome reporting requirements and regulations, unnecessary administrative costs, and program duplication.

Most importantly, this approach will enable the States to decide how program resources can best be distributed to meet the needs of their citizens, without the burden of Federally-mandated service delivery methods, organizational structure, and service and target group priorities.

The consolidation of many Federal social services grant-in-aid programs into a block grant is an important element in the President's program. The social services block grant consolidates 12 major social service authorities into a single block grant authority covering the purposes of the consolidated programs.

Block grant funds would be available to assist States in fostering individual self-sufficiency and economic self-support; assisting families and promoting family stability; reducing neglect, abuse, or mistreatment of vulnerable persons; promoting independent living where possible and assuring institutional care where needed; and stimulating improved use of private and public resources in the provision of social services.

The social services block grant consolidates authorities for ten major social service authorities administered by the Department of Health and Human Services: social services, day care, State and local training, child welfare services, child welfare training, foster care, child abuse prevention and treatment, adoption assistance, developmental disabilities, and runaway and homeless youth.

Two authorities currently administered by other Federal agencies also are consolidated: the Community Services Administration's activities, except for those related to community economic development, and Vocational Rehabilitation Services.

Our budget request for the consolidated block grant authority represents 75 percent of current funding levels for the 12 major authorities, or $3.8 billion being consolidated for fiscal year 1982.

The proposed legislation will provide authorization for $3.8 billion for each year through fiscal year 1985. Each of the current funding authorities for these activities will be repealed when this Act becomes effective. Each State's allotment from appropriations for a fiscal year will bear the same ratio to the total appropriation for that fiscal year as the State's share of the total amount allotted for fiscal year 1981 under the 12 major authorities being consolidated.

All services presently being provided through the categorical programs could be provided by the States under the social services block grant. Most delinquency prevention services and services to minors in the justice system presently authorized under the Juvenile Justice Delinquency Prevention Act could also be provided under the social services block grant, just as they are currently authorized under title XX of the Social Security Act.

We believe that this approach to social services will resolve several problems caused by the multiple categorical nature of the present Federal-State social service programs. First, it allows

States and localities the flexibility they need to distribute social services funds and to give priority to services which best meet the needs of the residents of that State.

Second, by eliminating many burdensome Federal administrative requirements, standards, and the like, the block grant will permit more efficient State and local administration and more effective services delivery systems. This will free resources for providing services and improving the management and delivery of services. In addition, the 10-percent transfer between block grants will enable the States to target those activities which they deem most important.

Under the block grant, States and localities will be in a much better position to take action where previously mandated program requirements and overlapping services have resulted in a waste of service dollars. State and local officials will also have the flexibility to respond to new and changing conditions, or to adjust to local conditions where, in the past, nationwide requirements have limited their options.

An example will illustrate the practical difference a block grant could make. Both title XX and the Rehabilitation Act presently authorize Federal assistance for employment-related training and supporting services to individuals and their families. Federal assistance for these services presently involve two different matching rates—75 percent under title XX and 80 percent under the Rehabilitation Act—at least two separate State agencies, four distinct State plans, and dozens of diverse administrative requirements. Under the social services block grant, States would operate under one set of rules and plans, with no matching rate. They would be able to determine the most effective means of providing services, with substantial savings in direct and indirect costs.

The block grant proposal requires the States to make available each year a report on the intended use of these funds prior to the expenditure of funds. This report must be made available within the State for comment by the public and by public agencies.

In addition, each State will be required to prepare, at least once every 2 years, a report on the activities carried out under the Act. This report must be made available to the public, and this would of course include State and Federal agencies.

The proposal also contains audit requirements. Each State is required to perform, at least once every 2 years, an audit of its expenditurse under the act. This audit must be carried out by an entity independent of the agencies administering the programs under the act. The audit report must be submitted to the State legislature and the Secretary of the Department of Health and Human Services within 30 days after completion of the audit.

We also plan to consolidate the funds for maintaining the necessary Federal support activities where they can be of most assistance to States and localities. Many of the statutory categorical authorities proposed for inclusion in the block grant also cover research, training, and demonstration projects to improve the administration and services delivery systems of these programs.

The activities to be consolidated are the research and demonstration activities under the child welfare services program; child abuse and neglect discretionary funds; runaway and homeless

youth discretionary funds, particularly the nationwide "hotline" for runaway youth; adoption opportunities activities, particularly for operation of an adoption information exchange; social services research and demonstration authority; university-affiliated facilities and special projects under the developmental disabilities program; research conducted by the National Institute for Handicapped Research.

Another effective role for the Federal Government is to share information and techniques among States. We can investigate new and innovative ways of delivering services to improve the effectiveness of social services programs. As the States are better able to coordinate service delivery under the services block grant, we will be able to coordinate Federal research, training, and demonstrations to support them.

There are also important nationwide projects contained in these authorities. As part of the consolidated discretionary activity, authority will be proposed for ongoing projects of national or regional significance, including the national telecommunications network to assist runaway and homeless youth, and the national adoption information exchange system.

Many of the discretionary activities currently being consolidated can be carried out by the Federal Government under this flexible discretionary authority and under section 1110 of the Social Security Act.

For example, the Federal Government could continue to respond to the needs of the developmentally disabled through the identification of more effective methods of providing services, funding special demonstrations to investigate innovative services and multidisciplinary approaches, the provision of demonstration results and training to the States in services delivery and management of programs for the developmentally disabled, and through the dissemination to and among States of information on new technology.

At the same time, the States will have the authority, under the block grant, to fund service programs for the developmentally disabled, to provide training for personnel to work in those programs, and to coordinate services needed by the developmentally disabled, such as is done now through the State DD councils.

In conclusion, Mr. Chairman and members of the committee, I want to emphasize that this administration maintains its commitment to provide assistance to those most in need in this country. But we also believe that we must reassess the ways in which we provide that assistance. Our resources are limited, and we must look for the most effective ways to use those resources. We believe that our proposals will achieve that, by providing the flexibility and funding to the states for social service programs to enable them more directly to design and control their programs to better serve the needs of their residents.

This concludes my testimony. I would be pleased to answer any questions you may have.

Senator RANDOLPH. Mr. Chairman, may I please interrupt?

Senator WEICKER. Absolutely, Senator.

Senator RANDOLPH. I do know that guests are here who are intensely interested in the subject matter. We have many chairs that are not occupied, and it is only a suggestion that those at the

door who are helping people to be seated know that there are 10 or 12 seats that are not occupied.

Senator WEICKER. On page 7—I just want to make sure that we are all on the same wavelength here—on page 7 of your testimony, where you list the activities to be consolidated, aside from that sentence which states, "University affiliated facilities and special projects programs under the developmental disabilities program," what else under DD—I do not understand where the other activities of developmental disabilities are included.

Ms. HAWKES. Mr. Chairman, this is the consolidated discretionary authority. The other activities under the developmental disabilities program are consolidated into the social services block grant which will be allocated to the States. Page 7 relates to Federal support.

Senator WEICKER. Now, in the social services block grant you describe, will there be any obligation on the States to provide services to persons with developmental disabilities?

Ms. HAWKES. There will not be an obligation. There will be an ability to serve.

Senator WEICKER. There is no obligation?

Ms. HAWKES. No; there is not.

Senator WEICKER. What compelling reason can you provide to explain why some Federal categorical presence is not necessary with respect to a vulnerable population such as persons with developmental disabilities?

Ms. HAWKES. Well, our experience indicates that States are serving people with developmental disabilities in many ways, not all of which are limited to Federal support programs. In fact, in looking through the various Federal dollars and State and local dollars being spent for people with developmental disabilities, the State/local match is much larger than the Federal dollars going into those programs.

Senator WEICKER. Are all 50 States operating on that basis that you described?

Ms. HAWKES. Yes.

Senator RANDOLPH. That is right, 90/10.

Senator WEICKER. Now, what happens if such services are not provided by a State? I am talking about the services to persons with developmental disabilities. What if they do not provide such services under your plan?

Ms. HAWKES. Well, I am trying to get to where you are. In order for States to decide——

Senator WEICKER. Very simply. There is no difficulty—I think the question is very direct and very straightforward.

Ms. HAWKES. In order to decide that they are not going to serve the developmentally disabled, States would have to repeal and change a total system that they have set up within their States now that are not directly related to the Developmental Disabilities Act.

Senator WEICKER. Well, as this administration knows better than anybody else, there is a system, and there are dollars, and the system can stay in place. What if they do not choose to go ahead and appropriate the dollars?

Ms. HAWKES. I guess I would find it hard to believe that they would not, since they are currently spending more than the Federal Government.

Senator WEICKER. Well, they did not. They did not used to go ahead and supply the dollars. That is exactly why you have this program. So I do not think I am unreasonable when I ask what it is that is going to happen should they not go ahead and supply the dollars.

Ms. HAWKES. Well, the requirements under the social services block grant are that the States indicate how they are intending to spend the funds under that funding mechanism. One of the requirements is that they produce a public report and provide for public input into the process. For a State to make that decision, they would have to make that decision in light of public exposure——

Senator WEICKER. Oh, I have no doubt that it will be publicly known that they are not spending the dollars. I have no doubt about that.

You see, my problem is that, as you know, even now, to remove this from the Federal side, even now as the battle for the dollars—as the dollars diminish and the battle grows at the local level, the minorities of our society—in this sense, now, I am talking about the disabled, the retarded, et cetera; I am not using it in an ethnic concept—are the ones that are left at the starting gate. And everybody knows it, but then everybody realizes also that their decision will be ratified by the majority at the polls. And unfortunately, we know all along what we are dealing with here is a minority in a political sense.

So my question again is what happens if the moneys are not appropriated?

Ms. HAWKES. I do not think I can answer what happens——

Senator WEICKER. Oh, I think you can answer it. I think the answer is "tough." That is what the answer is going to be. There is no other answer. Now, you see, there is the basic concern. There is the basic concern. And that is why I used—I am not wedded to this system. That is why, in my second question, I said there should be some kind of a categorical presence. Maybe there is some other mechanism that will guarantee that these people will not be left at the starting gate. But there certainly is no guarantee, at least as I read your testimony here today.

Senator Randolph.

Senator RANDOLPH. I want to pursue some of these matters. My difficulty, Mr. Chairman, is that I am supposed to testify at 10 a.m. I wonder if, in connection with this matter, Mr. Chairman, I can provide questions to be answered in writing to this subcommittee.

Would that be agreeable?

Senator WEICKER. Of course.

Ms. HAWKES. Certainly.

Senator RANDOLPH. And there are several questions that we do want to ask in reference to your testimony.

I was waiting for this opportunity—not to interrupt, Mr. Chairman—to say that because of those witnesses who are testifying today on matters that are of direct concern in our own State, that if you would permit me to direct written questions to not only our

witness now, but other witnesses; we would like to question them in several matters.

Would that be agreeable?

Senator WEICKER. That would be agreeable to the Chair. Those questions will be submitted not only to this witness, but to subsequent witnesses for response to the Senator, to the record. We will just handle it in that fashion.

Senator RANDOLPH. Thank you very much.

[The prepared statement of Ms. Hawkes and responses to questions from Senator Randolph follow:]

STATEMENT

BY

TERESA HAWKES

ACTING DIRECTOR
OF
THE OFFICE OF PROGRAM
COORDINATION AND
REVIEW

OFFICE OF HUMAN DEVELOPMENT SERVICES

DEPARTMENT OF HEALTH AND HUMAN SERVICES

BEFORE THE

SUBCOMMITTEE ON HANDICAPPED

COMMITTEE ON LABOR AND HUMAN RESOURCES

UNITED STATES SENATE

THURSDAY, APRIL 30, 1981

87-271 O—81——2

MR. CHAIRMAN AND MEMBERS OF THE COMMITTEE:

I want to thank you for this opportunity to appear here today to give you an overview of the Administration proposal to create a Social Services block grant. I am Teresa Hawkes, Acting Director of the Office of Program Coordination and Review, in the Office of Human Development Services. With me is (are)
I have a brief overview statement, and would also be pleased to answer any questions you may have.

This Social Services block grant proposal is a part of the larger program the President has outlined -- a package of initiatives designed to restore the health and vigor of the national economy. The most important thing we can do, not only for the groups we are concerned about in the social service programs, but for all citizens, is to put the nation's economy on a sound footing and reduce the inflation that makes economic self-sufficiency so difficult for so many people.

At the same time, this Administration retains a strong commitment to provide assistance to those most-in-need members of society, who without that support would lack the most basic necessities of life.

However, the present categorical program structure is cumbersome and inefficient. Resources that should be used for services are being used for meeting multiple and often conflicting Federal administrative requirements. The differences in eligibility make it extremely difficult for service programs to meet multiple needs of clients, or to refer them from one program to another. States do not have the flexibility they need to target resources on problems which they regard as most important.

For these reasons, we have chosen a new approach for providing Federal resources for a variety of social services. This approach -- the block grant -- is designed to eliminate the burdensome reporting requirements and regulations, unnecessary administrative costs, and program duplication.

Most importantly, this approach will enable the States to decide how program resources can best be distributed to meet the needs of their citizens, without the burden of Federally-mandated service delivery methods, organizational structure, and service and target group priorities.

The consolidation of many Federal social services grant-in-aid programs into a block grant is an important element in the President's program. The social services block grant consolidates 12 major social service authorities into a single block grant authority covering the purposes of the consolidated programs.

Block grant funds would be available to assist states in fostering individual self-sufficiency and economic self-support; assisting families and promoting family stability; reducing neglect, abuse, or mistreatment of vulnerable persons; promoting independent living where possible and assuring institutionally care where needed; and stimulating improved use of private and public resources in the delivery of social services.

The social services block grant consolidates authorities for ten major social service authorities administered by the Department of Health and Human Services:

- o Social Services
- o Day Care
- o State and Local Training
- o Child Welfare Services
- o Child Welfare Training
- o Foster Care
- o Child Abuse Prevention and Treatment
- o Adoption Assistance
- o Developmental Disabilities
- o Runaway and Homeless Youth

Two authorities currently administered by the other Federal agencies also are consolidated:

- o The Community Services Administration's activities, except for community economic development, and
- o Vocational Rehabilitation Services

Our budget request for the consolidated block grant authority represents 75 percent of current funding levels for the twelve major authorities, or $3.8 billion being consolidated for Fiscal Year 1982. The proposed legislation will provide authorization of $3.8 billion for each year through Fiscal Year 1985. Each of the current funding authorities for these activities will be repealed when this Act becomes effective. Each State's allotment from appropriations for a fiscal year will bear the same ratio to the total appropriation for that fiscal year as the State's share of the total amount allotted for Fiscal Year 1981 under the 12 major authorities being consolidated.

All services presently being provided through the categorical programs could be provided by the States under the social services block grant. Most delinquency prevention services and services to minors in the justice system presently authorized under the Juvenile Justice Delinquency Prevention Act could also be provided under the Social Services block grant, just as they are currently authorized under title XX of the Social Security Act.

We believe that this approach to social services will resolve several problems caused by the multiple categorical nature of the present Federal-State social service programs.

First, it allows States and localities the flexibility they need to distribute social services funds, and to give priority to services which best meet the needs of the residents of that State. Second, by eliminating many burdensome Federal administrative requirements, standards, and the like, the block grant will permit more efficient State and local administration, and more effective service delivery systems. This will free resources for providing services and improving the management and delivery of services. In addition, the 10% transfer between block grants will enable the States to target those activities which they deem most important.

Under the block grant, States and localities will be in a much better position to take action where previously mandated conflicting program requirements and overlapping services have resulted in a waste of service dollars. State and local officials will also have the flexibility to respond to new and changing conditions, or to adjust to local conditions where, in the past, nationwide requirements have limited their options.

An example will illustrate the practical difference a block grant could make. Both title XX and the Rehabilitation Act presently authorize federal assistance for employment-related training and supporting services to individuals and their families. Federal assistance for these services presently involve two different matching rates (75% under title XX and 80% under the Rehabilitation Act), at least two separate State agencies,

four distinct State plans and dozens of diverse administrative requirements. Under the social services block grant, States would operate under one set of rules and plans, with no matching rate. They would be able to determine the most effective means of providing needed services, with substantial savings in direct and indirect costs.

The block grant proposal requires the States to make available each year a report on the intended use of these funds prior to expenditure of funds. This report must be made available within the State for comment by the public and by public agencies.

In addition, each State will be required to prepare, at least once every two years, a report on the activities carried out under the Act. This report must be made available to the public; this would of course include State and Federal agencies.

The proposal also contains audit requirements. Each State is to perform, at least once every two years, an audit of its expenditures under the Act. This audit must be carried out by an entity independent of the agencies administering the programs under the Act. The audit report must be submitted to the State legislature and the Secretary of the Department of Health and Human Services within 30 days after completion of the audit.

Consolidated Discretionary Authority

We plan to consolidate the funds for maintaining the necessary Federal support activities where they can be of most assistance to States and localities. Many of the statutory categorical authorities proposed for inclusion in the block grant also cover research, training, and demonstration projects to improve the administration and services delivery systems of these programs.

The activities to be consolidated are:

- o Research and demonstration activities under the child welfare services program;
- o Child Abuse and Neglect discretionary funds;
- o Runaway and Homeless Youth discretionary funds, particularly the nationwide "hot-line" for homeless youth;
- o Adoption opportunities activities, particularly for operation of an adoption information exchange;
- o Social Services research and demonstration authority;
- o University Affiliated Facilities and Special Projects programs under the Developmental Disabilities program;
- o Research conducted by the National Institute for Handicapped Research.

Another effective role for the Federal Government is to share information and techniques among States. We can investigate new and innovative ways of delivering services to improve the effectiveness of social services programs. As the States are better able to coordinate service delivery under the services block grant, we will be able to coordinate Federal research, training and demonstrations to support them.

There are also important nationwide projects contained in these authorities. As part of the consolidated discretionary activity, authority will be proposed for ongoing projects of national or regional significance, including the national telecommunications network to assist runaway and homeless youth, and the national adoption information exchange system.

Many of the discretionary activities currently being carried out under the authorities being consolidated can be carried out by the Federal Government under this flexible discretionary authority and under Section 1110 of the Social Security Act.

For example, the Federal Government could continue to respond to the needs of the developmentally disabled through the identification of more effective methods of providing services, funding special demonstrations to investigate innovative services and multi-disciplinary approaches, the provision of demonstration results and training to the States in services delivery and management of programs for the developmentally disabled, and through the dissemination to and among States of

information on new technology.

At the same time, the States will have the authority, under the services block grant, to fund service programs for the developmentally disabled, to provide training for personnel to work in those programs, and to coordinate services needed by the developmentally disabled, such as is done now through the State DD Councils.

Conclusion

In conclusion, Mr. Chairman, I want to re-emphasize that this Administration maintains its commitment to provide assistance to those most in need in this country. But we also believe that we must reassess the ways in which we provide that assistance. Our resources are limited, and we must look for the most effective ways to use those resources. We believe that our proposals will achieve that, by providing the flexibility and funding to the States for social service programs to enable them more directly to design and control their programs to better serve the needs of their residents.

This concludes my testimony. I will be pleased to answer any questions you may have.

Response to Questions from Senator Randolph

Question: You note in your statement that "all services presently being provided through the categorical programs could be provided by the States under the social services block grant." However, since handicapped persons represent a minority, States may well decide to serve another and more vocal population. Since the President has pledged that the "truly needy" will not be hurt by his economic program, how do you reconcile that pledge with the likely result in terms of a lack of services to handicapped persons if the block grant proposals are enacted?

Answer :

- The current rehabilitation services and developmental disabilities programs have been extended as categorical programs in both the Senate and House versions of the Reconciliation Act.
- Therefore, specific programs and amounts to be used by the States in services to handicapped persons will be continued through these categorical programs.

Question: One of the stated purposes of the social services block grant is to assure "appropriate institutional care where needed. How do you define "appropriate institutional care?"

Answer:

- Appropriate institutional care has two major elements:
  - that the persons be placed in the least restrictive setting, and
  - that an active treatment plan for rehabilitation be developed and carried out.

Question: As you know, one of the basic thrusts of the Rehabilitation Amendments of 1978 was the emphasis on comprehensive services for independent living. How does the Administration intend, through its block grant legislative initiatives, to facilitate the continued development of programs to enhance opportunities for handicapped individuals to increase their capacity for living independently and for working.

Answer :

- Since the Rehabilitation Act has been extended as a categorical program in both the Senate and House versions of the Reconciliation Act, independent living program issues will be dealt with in the context of the continuing program.

Question: Assuming that the social services block grant is enacted, how do you plan to accomplish an orderly transition at the State level from categorical programs to block grants?

Answer :

- We do not anticipate major problems in transition, since States now administer through categorical programs 90% of the funds consolidated in the blocks, and since services allowable under these programs would remain eligible under the blocks.

- Over the past months, we have been working with the National Governors association, the National Council of State legislatures, the American Public Welfare Association and with other representatives of State government to identify their needs for information and to smooth the transition to the block grant.

- Among the things we are doing are giving States lists of current grantees within their jurisdictions, and identifying those cross-cutting Federal requirements that would remain in effect.

- Our Principal Regional Officials and Regional Administrators are in constant communication with Governors' offices and State agencies, providing information, arranging conferences which serve as policy and planning forums and potential solution.

- We will also be giving flexible planning grants to States to assist them in implementing the block grant in their jurisdictions. These grants will allow State representatives to travel to other States to identify effective practices that could be transferred.

- In both the Regional Offices and headquarters we have been meeting with groups representing the private sector in order to establish the partnership between the public and private sectors that will be important to the successful implementation of the block grant.

Senator WEICKER. Senator Nickles.

Senator NICKLES. Thank you, Mr. Chairman.

Ms. Hawkes, I listened to your testimony with interest. I thank Senator Randolph, and I also appreciate your past endeavors in this area, because I have a very, very stong and warm spot, I guess, for the handicapped. I guess we all specialize in different areas, and currently in the State of Oklahoma where I have been active, we have a center that I am most proud of and happen to be very instrumental in their continuation. It is an opportunities school for retarded children, and it is funded primarily with private funds. Also in the State of Oklahoma, where I served in the legislature, I have a great deal of confidence in the, I guess if you want to call it the political power of handicapped groups of people, because having served in the State legislature, I know where priorities are in many cases, but there is a very strong heartfelt support, I think, for the disadvantaged in this area. And I feel that if the word is "tough" if the services are not provided, I would think it would be not so much toward those people, but I think it would be toward the legislature and the Governor and the people in the local communities who did not provide the services that they were providing, because I think that they basically are going to have the moneys available to them, and they are going to have greater flexibility over the moneys that are available to them, and the amount of money in proportion. Can you give me a better feel of the total amount of money that is going to be going to them in block grants and possibly what percentage of that has been in the past for handicapped, and then we will maybe have a better idea of how they decide to divvy up the pie.

Ms. HAWKES. Under the developmental disabilities program as it currently operates, approximately $62 million is allocated. Forty-three million dollars of that is in direct grants to States, for administration and services. Approximately 35 percent of that $43 million is spent in administration and planning activities, and 65 percent in services.

But if we look at the total amount of Federal dollars and State-local dollars being spent for developmental disability services, under such programs as title XIV, medicaid, ICF MR, SNIFS, ICF's, title XX, Rehabilitation Services, Public Health Service, SSI, Head Start, CHAMPUS, AFDC Foster Care, and activities such as that, the total in Federal expenditures in 1980 was approximately $4.5 billion. The State and local costs in those areas were approximately $6.2 billion. So the State-local share in expenditures for developmental services was much larger than the Federal share.

Senator NICKLES. The States are already providing more money, then, than the Federal Government?

Ms. HAWKES. That is correct.

Senator NICKLES. But the developmental disabilities was only $62 million out of $4.5 billion?

Ms. HAWKES. It is $62 million out of the total Federal expenditures. $4.5 billion, that is correct.

Senator NICKLES. So, basically, if we threw this in the block grant approach, for 1982, I guess the Federal Government would be sending to the States block grants they divvied up the way they want to, $3.5 billion?

Ms. HAWKES. Yes, $3.8 billion.

Senator NICKLES. And if the individual States of the 50 States, then, out of the $3.8 billion, maintain a contribution of more than $60-some million, which is less than a percent——

Ms. HAWKES. Of the $4.5 billion.

Senator NICKLES. Less than a percent of the total package, then they will be maintaining the status quo. And if my guesstimate is right, the legislators and Governors, et cetera who will feel very close to their individual schools and to the children and the people they are trying to help, it is quite possible that they will allocate a much greater percentage of that fund to help these children; do you think that might be the case?

Ms. HAWKES. I think that might very well be the case. I think that the important thing to look at with the block grant is that they will have the ability to spend the money on services rather than on the coordination functions that now occur within the separate States by having separate departments of social welfare, social services, developmental services or mental retardation; you have a number of agencies serving the same population.

Our intent in providing this kind of an approach is that those services would be coordinated. Rather than having two or three bureaucracies serving the same population, the State could now have one system serving the population.

Senator NICKLES. If the States did somewhat reorganize—and here again, serving in the State legislature, I had serious concerns in some of these groups with the amount of dollars that were actually burned up in administration and not going to help the children we were trying to help—do you think most of the States would be responsible enough to eliminate some of the duplication in administrative efforts and actually go in and have some of these funds going in to help the people that we are trying to help?

Ms. HAWKES. That is certainly our intent, and part of the approach of the block grant is that a lot of those duplications and overlaps currently are required under Federal law.

Senator NICKLES. They are mandated by Federal law?

Ms. HAWKES. That is correct. So we are trying to eliminate some of the requirements for plans. For instance, as I mentioned, we have four separate plans and totally separate systems. Under the block grant, you could provide a consolidated plan and approach for meeting all of the needs. So that should enable them to eliminate a lot of that.

Senator NICKLES. Your figure for State and local costs being much greater than the Federal costs, I am thinking back to this project that I was involved in in Oklahoma that we had a fundraising drive for, to build this building for mentally retarded children, actually in my hometown, and I was cochairman of this fundraising drive, so I am very, very close to that, and I started to allude to it earlier. We made a mistake; to be truthful, several years ago, we decided we would apply for a Federal grant to help build this building. They required an extensive amount of regulation that delayed the building of this building. We eventually got the grant, but the time delays, plus the requirements for the way they wanted us to build a ramp, the way they wanted us to build the building, in fact, to be real truthful, we didn't build the build-

ing; we finished the basement. This was several years ago. To complete the building, we recently decided that we would make a drive to build the building, but we would not apply for Federal funds because there were so many strings attached that we found it to be prohibitive.

Do you think maybe some of this—I am going to say bureaucratic interference with actually, here again, local communities trying to help those who cannot help themselves, will be eliminated?

Ms. HAWKES. That is certainly the approach we are taking. Our expectation is that with states having the flexibility to allocate those funds and being tied in much more closely to the local communities, they would be able to be much more responsive to those kinds of efforts.

Senator NICKLES. The case that I am thinking of—and I am very, very sincere when I mention this—I notice you said that you hope, and I hope also, and I want to work with you and to insure that it is, because this was a disaster, as far as I was concerned. We lagged 5 years. We are just now finishing this building. We were actually building the building to do some work projects to help these kids help themselves physically and mentally and also produce a little product and earn a little money—this was mentally handicapped, primarily—and basically, the Federal Government frustrated our efforts in the community to do that by several years, and in my instance, I think they penalized the kids, primarily, and young adults in this case, too.

So I think it is important that we do eliminate those. I think the block grant approach would do a lot for that, because when the community leaders including myself were knocking on the door of the Federal Government, we found very little response. I think they will find better response if they run into these roadblocks in talking to their State legislatures, to their representatives, to their city council and the lower levels of government, instead of trying to coordinate out of Washington, D.C. I think it is very difficult.

So I commend you and the administration and the chairman, for his concern, because I think we all can work together. I think we have a common objective, and that is to help those who cannot help themselves. And I am optimistic that possibly, you are making a good step in the right direction for that.

Also, when I look down at the total amount of moneys that was going out for developmental disabilities, and I see the $62 million out of $4.5 billion, it seems to me that priority—wise, it was very low. And I am optimistic that the States will do some shuffling within the block grants and actually increase it for particularly the mentally and physically handicapped. I think we could see a real change in priorities basically coming from that sector that will be of real benefit.

Thank you, Mr. Chairman.

Senator WEICKER. Thank you very much for your testimony, Ms. Hawkes.

The next panel, entitled "Persons With Development Disabilities", will have on it Elizabeth Boggs, a member of the New Jersey Council on Developmental Disabilities and the National Council on the Handicapped; and Emmy McClelland, a member of the Missou-

ri Council on Developmental Disabilities, and the parent of an autistic child.

Now, we have before us during the course of this morning five panels. And what I would like to do is to make certain that everybody gets heard. In that regard—and I will say this only once—all statements in their entirety will be included in the record. And I would appreciate it if the panelists could summarize their statements, try to keep those statements within the 10-minute mark, thus leaving some time for questions, which I think are probably the most instructive to us who are the laymen in regards to the technicalities and the specifics of what it is we are holding this hearing on.

Yes, Senator Nickles.

Senator NICKLES. Mr. Chairman, I have been informed that I have another meeting where they need a statement from me. I will try to return as promptly as possible, because I am very, very interested in this subject, and I am very sincere and serious. I appreciate your holding these hearings. And to the witnesses, if I miss part of your testimony, I will read it, and hopefully, I will be able to get back to visit with you.

Senator WEICKER. Thank you very much, Senator Nickles.

Elizabeth Boggs, good morning to you. Please go ahead and proceed.

STATEMENT OF ELIZABETH M. BOGGS, PH. D., MEMBER OF NEW JERSEY COUNCIL ON DEVELOPMENTAL DISABILITIES AND THE NATIONAL COUNCIL ON THE HANDICAPPED; AND EMMY McCLELLAND, MEMBER OF MISSOURI COUNCIL ON DEVELOPMENTAL DISABILITIES, AND PARENT OF AN AUTISTIC CHILD

Dr. BOGGS. Good morning, Senator.

I am delighted to be present today a to witness the continuation of the bipartisan approach on the part of this committee, an approach which has characterized the full committee since the time of President Eisenhower, under both kinds of administration. It is heartening to have this attention to our subject matter, in a time when I know you have other very macro issues on your mind.

Mrs. McClelland and I may be regarded as experts at two levels on this subject matter, since we are both parents of very severely disabled persons. In my own case, my son is now 35, and he qualifies on all seven of the impairments in the definition of developmental disability.

We both serve on our respective developmental disabilities councils at the State level, and we have there an experience of looking at the group of persons with developmental disabilities collectively and looking at the needs collectively. In my own State, we had a regularly scheduled council meeting last week at which we examined, program by program, the impact of the proposed Federal changes in health, in education, in social services and rehabilitation, on our State programs. We discovered that some of our State programs have their own legislative base, and some of them have simply gone on for years on the assumption that the State had the prerogative of accepting the Federal funds, but there is no State statutory authority to do what they are now doing with Federal

funds. Our Council will address those issues over the next 2 or 3 months in its role as a coordinator and viewer across the board.

I have here a Federal publication which lists 60 programs which impact one way or another on people who are handicapped. Many but not all of those programs do impact on people who are developmentally disabled. And as the previous witness has said, they probably involve something in excess of $5 billion of Federal funds. The DD Act is designed to put a string, so to speak, through those beads that affect this particular population, to help the States to see how those things can be strung together.

President Carter once made what some of us thought was a rather unwise suggestion that the special aspects of these various programs should be extracted and consolidated into a separate program for the handicapped. That would be contrary to the concept of integration, because we now have housing for the handicapped as part of housing, we have health for the handicapped as part of health, and so on down the line. That reflects a socially integrated concept which we wish to preserve.

To come back to the needs of developmentally disabled persons, let me stress for a moment the importance of that criterion of age at onset. I have had experience with my own son, and I also have had experience with the later years of my two parents. My father was blind and almost deaf when he died. He had other impairments, but because of his prior experience as non-handicapped person he still was able to understand his situation and to decide that he would terminate the radiation treatment that he found objectionable. My son is not able to make that decision, and because he has no history of ever having had that capacity, I as his guardian am not allowed to make it for him.

There is a difference. There is a great difference in the economic, personal and legal status of people who become disabled later in life, on the one hand, and people who have been disabled since early childhood, on the other. And it is this latter group, whose members need lifelong attention and consideration, that are addressed in the Developmental Disabilities Act.

It is hard for people who do not know developmentally disabled people personally to visualize them, but I see a lot of audio visual equipment in the room here, and I think perhaps we will have a chance to visualize later in the session.

The people with developmental disabilities, by and large, have neurological disorders. This is not part of the definition, but in fact, when we look at them, we see that this business of early onset is related to the fact that the young child has a very vulnerable brain and nervous system. Consequently, this group with early onset has different characteristics, medically, socially, intellectually, economically, than people who become disabled later in life. Consequently, programs that are written for "the handicapped" are often not accessible to those severely disabled since childhood unless special advocacy is provided.

I would like to say a word or two about title XX, because we have had some experience with that, and I participated to some extent in formulating that Act.

We can identify at a minimum approximately $300 million, about 10 percent of the title XX money, which goes to special

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programs for people who are developmentally disabled, as a result of options at the State level. That is considerably larger than the money available under the DD Act. However, less than half the States are using that title XX money in that identifiable way. The other half of the States are not identified as using any title XX money, although they have had the option all along.

Under the proposed social services block grant, we would see, in effect, the consolidation of $50 million of DD money, $200 million as the DD pro rata share out of the billion of rehab money, and $300 million of present title XX money into a block grant that is similar in structure to the present title XX legislation. This does not give assurance that we can continue in every State the minimal level of support that we have experienced in the past under so-called categorical legislation.

It is easy to go the "macro" route and talk about $5 billion here and $6 billion there. A State such as Oklahoma, which has had in the past a low per capita income relative to the national average, has shared exceptionally well in Federal funding. And I know how some of the Federal monev has been used in Oklahoma, and I will be amazed if Oklahoma can manage to continue this sort of agenda without the Federal assistance.

It is necessary to deal at two levels, first the individual advocacy and personal coordination level, and second, the administrative planning and collective advocacy level. The need for special coordination at these two levels is directly related to the characteristics of the population as defined in the Developmental Disabilities Act. And it is that need which the act meets that other Federal programs do not address.

Senator WEICKER. Thank you very much.

[The prepared statement of Dr. Boggs follows:]

TESTIMONY

on the

EXTENSION OF THE DEVELOPMENTAL DISABILITIES ASSISTANCE

AND

BILL OF RIGHTS ACT

Mr. Chairman and Members of the Subcommittee on the Handicapped, I appreciate the privilege of being invited to appear before you in support of your initiative in seeking to extend the Developmental Disabilities Act. It is heartening to know that you are attending to our concerns in the midst of many other demands.

I would like to address the following five questions:

1. Why is some federal "categorical" presence necessary with respect to certain vulnerable populations even when (or especially when) a strong tide is flowing toward withdrawing federal support and direction in human services and toward devolution of responsibilities to the states and municipalities?

2. Why is the particular population which has been defined as developmentally disabled unique, and appropriate for special attention, and in what ways is the Developmental Disabilities Act different from other statutes, including many of those that refer to handicapped persons or which indeed include some persons with developmental disabilities as members of their eligible populations?

3. How do the specific features of the Act respond to the unique characteristics of the population as now defined?

4. Will consolidation into block grants save money that can be used for services?

5. What changes, if any, should be made in the Act at this time?

1. Why is some federal "categorical" presence necessary?

a) A federal presence is necessary to protect federal self interest. Nearly a billion dollars a year flows to approximately half a million identified persons with developmental disabilities who qualify for Supplementary Security Income. I attach a table prepared by the Social Security Admininstration showing beneficiaries in the categories of mental retardation, cerebral palsy, and epilepsy - typical diagnoses associated with developmental disabilities. (If it had been possible to identify additional diagnoses accurately with respect to age at onset, the estimate would have been higher.). About one-quarter of these recipients are children. Many children who are ineligible because of family income will eventually become eligible as adults if their disability is not alleviated. It is in the federal interest even more than in the states' interest to assure comprehensive and timely interventions in the lives of these persons at every point along their life span where modification of the life trajectory can be effectuated. Eventually, the federal government will pay more than the states for dereliction at the state level. Moreover, since developmentally disabled persons, like other citizens, have freedom of movement, failures by one state to alleviate disability may impose a later burden on another.

b) Federal categorical programs on behalf of specific groups such as dependent children, the frail elderly, the blind, the chonically mentally ill, and the developmentally disabled have come into

being during the last seventy years because the special vulnerabilities of these groups were not being adequately addressed, for whatever reason, at the local and state level. The inequities as between states have been notorious.

c) In the case of the developmentally disabled (and the chronically mentally ill) serious abuses have occurred, for some of which public bodies have been responsible; while there may be some doubt as to whether the United States should be attempting to advise other nations on the subject of human rights, there can be no doubt that our own system of checks and balances should be invoked and brought into play at every level where violations of the human and civil rights of our own citizens are at issue.

2. What is unique about those we call developmentally disabled?

a) Persons with severe disabilities originating early in life have a different life experience than do persons who become disabled only after education is complete and some vestment in employment established. Indeed, most disabled adults spend a relatively small portion of their life span in that condition, whereas almost all those we call developmentally disabled cannot remember what it was like not to be disabled. It does make a difference.

b) I am not an attorney, but early in my thirty years as a volunteer in this field, I came to understand the basic principles of classification in legislation. A class of people may be singled out for special attention by government if the class is defined reasonably in relation to the social purposes of the legislation. In 1975

this Subcommittee asked for an independent study to address the "appropriateness" of a definition of developmental disabilities to be used in this Act. Such a study was commissioned; its participants included handicapped persons who did not look upon themselves as developmentally disabled as well as spokespersons for those who clearly were. In developing a "functional" definition the study participants considered the most vulnerable group to be those with substantial limitations in at least three major areas of life activity, giving rise to a need (by the individual) for "a combination and sequence of special, interdisciplinary or generic treatment or other services which are of lifelong or extended duration and are individually planned and coordinated..." Congress enacted this definition in 1978. Thus the need for sustained participation across systems, across agencies, across disciplines is, by definition, characteristic of this population more than any other.

c) America's evolving national policy on disability has been dominated by the image of disability impacting on the heretofore self-sufficient self-supporting adult, the family man or woman, the worker who becomes disabled. It is true that we have also felt compassion for the handicapped child, the courageous little tyke on the telethon, with the capacity for success if only we will give, but our national policy has seldom addressed the needs of those children whose childhood handicaps become adult disability, aggravated by the impairment of the developmental process itself, by the difficulty of establishing one's identity as a free-standing human being and often by the limited options for forming a new contemporary family. We have not

attended to the need for continuity of social support over the major life transitions. There is no other federal program for handicapped people that bridges these transitions.

d) Ten years ago the Congress addressed these problems in the original Act. The Developmental Disabilities Act is not just another channel through which money can be directed to reach a particular constituency. It is a unique system for tapping resources created under other state (and federal) statutes for people generally. In an era of shrinking resources such a focal point is needed more than ever.

There are many parallels between the Developmental Disabilities Act and the Older Americans Act. Just as the "big money" for the elderly does not flow through the Older Americans Act, so neither does big money flow through the Developmental Disabilities Act. These Acts are important because they foster focal points of concern for and expertise in the special problems that go with a certain kind of vulnerability. These pieces of legislation are even more important when resources are diminishing. The legitimate arguments for preserving the Older Americans Act are also valid for the Developmental Disabilities Act.

3. How do the specific features of the Act respond to the target population?

a) The requirement for a state council in each participating state addresses the need for cross-cutting at the level of planning. A typical council will include representatives of six to ten departments or principal agencies of state government along with consumers

and consumer surrogates. Although it took some time to evolve this new model, the Councils have now become functioning bodies in most states, with stable staff and an understanding of planning as an on-going cyclical process. They are resources not to be thoughtlessly dismantled.

b) The requirement that each client have an individual habilitation plan addresses the cross disciplinary multi-resource model at the level of direct delivery to a unique individual. While good models for this device are still being evolved, the requirement is positive and relevant and not unduly intrusive.

c) The priorities specified in the Act, for early intervention, case management, alternative living arrangements and non-vocational services permit concentration of the very limited developmental disabilities resources on areas that are likely to be overlooked when the larger traditional state and federal money streams are allocated for education, vocational rehabilitation, social services, health care, and independent living for the self-directing handicapped.

4. Can consolidation into block grants save money that can be spent on services?

It is possible that it can, but unlikely that it will.

a) Our experience with general revenue sharing was not encouraging.

b) In a closer analogy, it should be noted that most categorical legislation, including the Developmental Disabilities Act (Section

313(d)(1)) sets limitations on the amount a state may spend for administration. A block grant does not. Title XX, the prototype for the proposed $3.8 billion Social Services Block Grant (intended to absorb the $40 million allotted residual for the Developmental Disabilities program after revision of the 1982 budget) is instructive. In my own state of New Jersey we have been fortunate in the past to secure about almost $4 million of Title XX funding for community services for developmentally disabled children and adults. However, the state treasurer's claims for administrative costs are now in the vicinity of 25% of the total Title XX funding. Moreover, when retrenchment has been necessary, (as it has in several past years), we note that state-operated programs have been maintained while non-profit providers with whom the state writes purchase-of-service contracts are cut off without continuing funds, or expected to continue with reduced funding. Since a large share of the Developmen al Disabilities service dollars now flow to voluntary agencies or colleges we anticipate a high mortality among small voluntary agencies operating day centers, workshops, parent education, family support and homemaker services, local transportation and the like.

5. What changes are needed?

a) In general the Act has been the subject of too many changes in the past with too much specificity. I would propose changes only where there is strong consensus in that direction.

b) Considering the amount of money involved, (less than 2% of the amount of federal money reaching the target population through

other channels), the program has received an inordinate amount of scrutiny and regulation. While none of us would do away with reasonable evaluation criteria, the comprehensive evaluation system which has been evolved in reponse to the enactment of Section 110 in 1975 is an example of overkill, and places an excessive burden on the states. The House bill offers an acceptable alternative.

Finally, I would like to make mention of a provision which I would not like to see substantially revised. I refer to the requirement for independent protection and advocacy systems in each participating state (Section 113). It is clear that such systems cannot survive without the required independence in both funding and authority. Some Protection and Advocacy Systems have made mistakes of judgement. I am personally aware of positions taken in my own state and elsewhere with which I disagree, but like Voltaire, I defend their right to disagree, and I believe that it is useful to have substantive issues raised and clarified by negotiation, if possible, or, if necessary, by adjudication.

You have been supplied with a report* depicting the extent and diversity of activities of these bodies. Not least important is the unexpectedly large proportion of Protection and Advocacy staff time which has been spent in assisting individual parents to secure for their children the benefits intended under the Education for All

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* R. L. Henney and C. Alldredge: Protection and Advocacy in the United States - The First Three Years. Institute for Comprehensive Planning, Washington, 1981.

Handicapped Children Act, also a product of this Committee. Formal litigation has been used only as a last resort. Only 2% of all cases handled involve court action. As a matter of practicality, no Protection and Advocacy System can afford to mount major litigation while relying only on its share of the $7.5 million in available federal resources. The big suits, Partlow, Willowbrook, Pennhurst, and Plymouth, were brought by agencies, plaintiffs and attorneys having access to foundation or other private funding.

The fact that some state agencies may be uncomfortable when challenged by one of these Protection and Advocacy Systems should not be a surprise to you. It was this Committee's dismay and dissatisfaction with the inability of state agencies to police themselves that brought about your mandate that Protection and Advocacy Systems be created. The courts have demonstrated their ability to deal with excessive zeal as well as with patent neglect where it has occurred. I urge that you continue to assure that Protection and Advocacy Systems have sufficient resources to contend in the various arenas where representation for the voiceless is needed so that genuine two-sided dialogue can take place.

Developmentally disabled beneficiaries receiving payments under the supplemental security income program, 1977-1979

Disability	1977		1978		1979	
	Estimated 1/ number of beneficiaries	Estimated 2/ benefits (thousands)	Estimated 1/ number of beneficiaries	Estimated 2/ benefits (thousands)	Estimated 1/ number of beneficiaries	Estimated 2/ benefits (thousands)
Mental retardation..	388,131	$58,359	399,628	$61,870	404,912	$73,577
Cerebral palsy.....	33,750	5,075	34,750	5,380	35,210	6,398
Epilepsy.....	42,188	6,343	43,438	6,725	44,012	7,997
Autism.....	Not available	Not available	Not available	Not available	Not available	Not available

Source: Social Security Administration, Office of Research and Statistics

1/ Estimated number of persons receiving payments in December of specified year.

2/ Estimated monthly payments received in December based on average monthly payment - December 1977 ($150.36); December 1978 ($154.82); December 1979 ($181.71).

Senator WEICKER. Mrs. McClelland.

Mrs. MCCLELLAND. Thank you, Mr. Chairman.

My name is Emmy McClelland. I am from Webster Groves, Mo., which is a suburb of St. Louis. My husband and I are the parents of a 16-year-old son who has autism.

We in Missouri have long recognized two very important parts of the Developmental Disabilities Act. That is, one, the value of cooperative planning by both parents and professionals at the local level to provide services for the developmentally disabled, and two, the use of Federal funds to generate new moneys and to access other program funds to support services for the developmentally disabled.

Even though my son is 16 years old, it does not seem that long ago that my husband and I tried to find some type of services for him. It took us about 2 years of evaluations at various facilities to finally get a diagnosis that his handicapping condition was, and is, autism. We were told such things as: "He is severely retarded. Put him in an institution and forget you had him"; "We do not think he is deaf, but we are not sure, because he ws really difficult to test"; or, "Forget it; he will grow out of it. You will not have anything to worry about by the time he is 5 or 6 years old."

Fortunately, parents in Missouri today have 11 regional centers for the developmentally disabled which provide diagnosis and evaluation services. They are located in each region of the State. They were constructed in part, in the late 1960's, with funds from Public Law 88-164, which was a forerunner of our present Developmental Disabilities Act.

For us, receiving a diagnosis of autism for our son opened up a whole new set of problems. That is, trying to find a program that would accept him and provide him with a meaningful type of education, services, or therapy. We are fortunate that we lived in a large metropolitan area where some services were available to handicapped children. However, it took us about a year to find a program that would accept him. The programs for the retarded did not want him because his behavior was so bad. Programs that dealt mainly with language problems did not want him because he was "retarded." So, we were turned down by various programs.

I think I should emphasize that for a parent of an autistic child, getting him in to a program in a 3-year time period was a record-breaking feat. Most parents of autistic children do not have that much luck—especially the parents of handicapped children living in the rural areas of the State, where services in the late sixties and early seventies were very few and far between.

In Missouri, for example, we had at that time 37 sheltered workshops, a handful of community residential programs, preschool programs, recreation programs, and daycare programs. We had about 500 people in community residential placement.

As a parent and a member of our council, I am happy to report that we have made a lot of progress in the past 10 years. We now have 79 sheltered workshops, of which 42 were funded in part with developmental disabilities funds. We have funded over 100 various programs—for example, activity centers, preschool and infant stimulation programs—with developmental disabilities funds through 1-year subgrants to local not-for-profit organizations. We now have

over 4,000 individuals with mental retardation or with other developmental disabilities in community residential programs in the State.

We have developed in Missouri what we feel to be an effective network for planning, which involves both professionals, parents, and other advocates. We have 11 regional councils which are consumer-driven councils. Since 1975, they have been staffed with developmental disabilities funds. These councils serve as the arms and legs of our State council and provide grassroots input to the State council in the planning process for the service delivery system.

Perhaps the best way we work together is through open forums held every year at which time the State council, the chairmen of the regional councils, coordinators for the regional councils, and the regional center directors meet to discuss various issues of concern to the developmentally disabled. Last year, we came up with three priorities relating to service needs in the State. They were: Zoning—problems with putting group homes into R–1 zoning in the State—preschool programs; and transportation. And from this, the State council's legislative committee, which I chair, drafted three bills to address these issues. I have described in my written testimony the current status of these bills. I would like to say that they have all been passed, but they have not yet.

One of the activities that we are most proud of is the State council's support of counties to pass a mill tax levy to provide money for services for the developmentally disabled. In the State, 53 of the 115 counties have passed Senate bill 40, which is a county tax levy to support services for the developmentally disabled at the local level. The council is very actively involved with the regional councils in supporting passage of the levies. There are two things that I would like to point out. In this day and age of proposition 13, where no one, as far as the voters are concerned, wants to raise taxes, this past April, Senate bill 1140 was on the ballot in seven counties in Missouri. It passed in six of those counties.

So, as you can see, people are still willing to raise their personal property taxes to pay for services for the developmentally disabled.

The other thing that I would like to point out is that this year, the revenue generated by these county tax levies will exceed $10 million. Since Federal DD money began flowing into the State of Missouri in 1971, our total allocations for all those years combined has not yet reached the $10 million level.

In summary, I hope I have been able to show you how we in Missouri have used the flexibility of the developmental disabilities program to develop a fine network of cooperational planning involving parents and advocates for the developmentally disabled.

I would be remiss if I said that things are fine, and we have accomplished everything. We have not. We have laid the groundwork, and we have established a good foundation for services. However, our work has really just begun to see that adequate and appropriate services are provided for our population, especially the autistic, which was the last group to be brought into this category.

Thank you.

[The prepared statement of Mrs. McClelland follows:]

GENE WAITE
CHAIRMAN

Missouri Planning Council
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STATEMENT ON EXTENSION OF THE DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT

Testimony

Presented to
The Subcommittee on the Handicapped
of the Senate Labor and Human Resources Committee
United States Senate
Senator Lowell P. Weicker, Jr., Connecticut
Chairman

Respectfully Submitted
by

Emmy McClelland, Member
Missouri Planning Council for Developmental Disabilities
April 30, 1981

STATEMENT ON EXTENSION
OF DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT
APRIL 30, 1981

Mr. Chairman and Members of the Subcommittee:

My name is Emmy McClelland, and I am from Webster Groves, Missouri. My husband and I are the parents of a 16-year-old son who has autism. I am a member of the Missouri Planning Council for Developmental Disabilities. As both a parent and council member, I am here today to speak in support of the extension of the Developmental Disabilities Assistance and Bill of Rights Act as introduced by Senator Weicker.

In Missouri, we have long recognized two important aspects of the Developmental Disabilities Act: (1) The value of cooperative planning for services at the local level by consumers and providers and (2) The use of federal funds to generate new monies and to access other program funds to support services for persons with developmental disabilities. Today, I am pleased to share with you how we in Missouri have applied the spirit of the Developmental Disabilities legislation toward the establishment and improvement of programs and services in Missouri for persons with autism and other developmental disabilities.

Although our son is 16, it seems like only yesterday that we were first seeking services for him. It took two years of evaluations from a variety of agencies for us to learn what his handicapping condition is. Of course, we were given all kinds of advice such as:

"Don't worry, he'll grow out of it."

"We don't think he's deaf, but we're not sure because he was so difficult to test."

"He's severely retarded. Put him in an institution and forget you ever had him."

Fortunately, parents of autistic children and those with other developmental

disabilities can today take their children to one of eleven regional centers in our state to obtain diagnosis and evaluation services. Nine of these eleven centers, incidentally, were constructed in part with P.L. 88-164 funds in the late 60's. As you know, P.L. 88-164, the Mental Retardation Facilities and Community Mental Health Centers Construction Act, was a forerunner of our current Developmental Disabilities program. For my husband and me, however, receiving a diagnosis of autism created a whole new set of problems--trying to find a program that would accept our son and provide him with appropriate therapy and education. We were not interested in "entitlement" programs as such. We just wanted to find a program to enroll Mike in, fully intending to assume full financial responsibility and all other responsibilities for getting him there, etc. We felt privileged to live in a large metropolitan area with several programs for handicapped children. However, in making the rounds to find one that would accept our son, we soon heard statements like, "I'm sorry. We can't take him in our program. He's not retarded." "As soon as his behavior improves, bring him back and we'll work with him." "I'm sorry. He just doesn't fit into our program."

In looking at the state as a whole in the late 60's and early 70's, there simply were not very many programs for persons with developmental disabilities, especially for persons with autism. This was even more of a dilemma for parents living in rural Missouri.

As both a parent and Missouri Planning Council member, I am very happy to report to you that the Missouri Developmental Disabilities program has put a variety of programs into place statewide during the 10-year life of the Developmental Disabilities Act. At the time the original Developmental Disabilities legislation was enacted by Congress in 1970, there were only 37 sheltered workshops in our state. Only a handful of community residential programs, pre-schools, recreational services, and adult activity centers existed. In 1972, there were

only 526 persons with mental retardation placed in community residential programs in Missouri, primarily due to the lack of such community residences.

Today in Missouri, we have 79 sheltered workshop corporations in 90 locations, employing over 4,000 persons with developmental disabilities. Federal Developmental Disabilities funds were used to establish the 42 additional workshops. Today, there are 4,109 persons with mental retardation and other developmental disabilities placed through the Department of Mental Health placement program into community residential programs. These people participate in a variety of programs, including pre-schools, sheltered workshops, adult activity centers, and recreation programs. These programs and services are also available to persons with developmental disabilities who reside in their natural homes. Less than 2,000 Missourians (1,999) reside in the five state mental retardation institutions.

At this point, I want to emphasize the mutual commitment that the state agency (the Missouri Department of Mental Health) and the Missouri Planning Council have toward developing and implementing a continuum of services to include all the different levels of care which persons with developmental disabilities need. We recognize state institutions, various types of community-based residences, and natural homes as necessary components of the residential service delivery system. Of course, other direct and support services must be available to complement the residential programs.

The Missouri program has developed what we believe is an effective network for involving consumers and professionals in the planning and decision-making processes regarding programs and services for persons with developmental disabilities. Under the leadership of the Missouri Planning Council, eleven consumer driven regional councils were organized in the early 70's to provide grass roots input into determining and prioritizing realistic services objectives at both the regional and state levels. The eleven regional councils are viewed as the "arms

and legs" of the Missouri Planning Council. All eleven of these councils have been staffed through Developmental Disabilities funds since 1975.

Each of the regional councils develops and annually updates its plan for meeting the needs of developmentally disabled residents of its region. These regional plans, then, become the basis for the State Developmental Disabilities Plan. Last year, the Missouri General Assembly provided statutory authority for the regional councils to assist the Department of Mental Health and the Missouri Planning Council in assessing regional service needs and developing regional plans. This new statute also provides for the regional councils to review and advise on programs, budgets, and policies of facilities operated by the Department which serve the developmentally disabled.

The regional councils have, as a whole, been very successful in filling service gaps as indicated in their regional plans. To a large extent, this gap-filling involves generating applications for Developmental Disabilities funds to put needed services in place. In this regard, the councils' staff have either located or organized eligible applicants for funds, assisting those applicants in the preparation of applications and helping them to establish funded programs. Those staff persons also provide ongoing technical assistance for these new programs.

In 1971, virtually every regional council in Missouri identified sheltered employment as the number one service priority for most counties within its region. Today, none of the regional councils identify sheltered employment as a priority. In the few years of its existence, the federal Developmental Disabilities program has been directly responsible, through one-year sub-grants to local not-for-profit agencies, for the creation or expansion of more than 150 community programs in our state, including the many new sheltered workshops. The Missouri Planning Council and the regional councils have also been chiefly responsible for accessing the Title XX program, community-based Intermediate Care Facilities for the

Mentally Retarded under Title XIX, and Farmers Home Administration low-interest loans for programs serving persons with developmental disabilities.

Last year, the regional councils and the Missouri Planning Council identified three barriers to an effective statewide service system: Inadequate transportation, exclusionary residential zoning ordinances, and ongoing funding for early childhood education programs. Three pieces of state legislation have subsequently been introduced to address those problems. At this point, we may see passage of one of these bills. That bill would permit not-for-profit transportation corporations serving handicapped persons to use local matching funds to access state appropriated funds to help offset operational costs. Under the present state statute, state appropriated dollars can only be used to match federal transportation monies.

Although the bill to prohibit zoning discrimination against handicapped persons will probably not see passage this year, it has advanced farther than a similar bill did two years ago.

Perhaps the piece of legislation closest to my heart is the bill to require public schools to provide early childhood education to handicapped children whose parents want such services. As a parent, I can't emphasize enough the importance of pre-school programs for children with developmental disabilities, especially with autism. Recent data from an early intervention project for autistic children conducted by Dr. Ivan Lovas at UCLA suggests that about half the children in his program will approach normalcy because of the early intervention benefits they received through his program. Dr. Lovas stated that "the outcome of 50 percent of the students in the intensive treatment group looks very encouraging in the sense that they are functioning adequately with minimal help in a normal school setting." Although we in Missouri will not see favorable action on our bill this year due to our state's economy, we will continue to push for pre-school education.

Perhaps the area in which we as a council take the greatest pride is our support of counties to assist with public educational activities necessary to achieve passage of county tax levies to support a variety of needed services for handicapped residents of those counties. Fifty-three of Missouri's 115 counties now provide a variety of county-supported services for developmentally disabled persons through these tax levies. Establishment of all but two of these 53 county programs is directly attributable to the Missouri Planning Council and the regional councils, which have supported and otherwise worked for passage of the county levies. Such levy passage, of course, provides local control over local programs, reducing the need for dependence upon state and federal funding sources.

I am pleased to announce that voters in six of these 53 counties just passed mill tax levies this month. In this day of Proposition 13, it is rewarding to know that voters are still willing to increase their personal property taxes in order to support programs for the developmentally disabled. The total annual revenue generated within these 53 counties will exceed $10 million this year. It should be noted that since federal Developmental Disabilities funds began flowing into our state under the formula grant program in 1971, the cumulative total of allocations to Missouri for all those years has not yet reached that amount. We feel very strongly that the passage of the tax levies in these 53 counties alone is good return on the federal Developmental Disabilities funds invested in Missouri to date.

As you can see, the federal Developmental Disabilities legislation has provided us in Missouri with the flexibility needed to identify, plan, initiate, and fund badly needed programs and services for our citizens who have developmental disabilities. Also, probably no single piece of legislation has helped autistic persons more than the 1975 Developmental Disabilities Assistance and Bill of Rights Act, which, for the first time, included autism among the developmental disabilities. As a result of this inclusion, parents of autistic children could start accessing

services for their children through programs designed for the developmentally disabled and were able to impact on the service delivery system through membership on state planning councils for developmental disabilities.

As parents of a son with autism, my husband and I have jumped three major hurdles thus far: Obtaining an evaluation and diagnosis of Mike's condition, obtaining pre-school services, and accessing a public school education for him. Like most parents of children with developmental disabilities, we are faced with still other hurdles. The underlying concern and fear my husband and I now have is what the future holds for our son. What will happen to him after we are gone? Will he be able to hold a job? More importantly, where will he live as he grows older?

These are the types of parent questions the federal Developmental Disabilities Act addresses. The beauty of the Developmental Disabilities program is that it allows and advocates for parents along with service providers to answer these questions with an effective service delivery system forged through such cooperative efforts within each state.

In Missouri, the groundwork has been completed and the foundation laid for a comprehensive network of services for that population which was for far too long neglected--the developmentally disabled. Those of us whose children have autism are indeed playing "catch up," having been the last categorical disability added to the program.

As a parent and a member of the Missouri Planning Council for Developmental Disabilities, I ask the committee, on behalf of that council, to recommend extension of the Developmental Disabilities Act so that we may continue to build the capacities of service delivery systems in every state in the United States. Despite remarkable accomplishments throughout the country in the few short years since the first Developmental Disabilities legislation was enacted, our job has only begun.

Senator WEICKER. Thank you very much.

The question I would pose to both of you, since both of you have children who had their particular difficulties prior to the initial passage of the act, and therefore lived under the system that existed then, and lived under the system that exists with the DD Act, I would now like to have your views, each one of you responding to the question, as to what you envisage under a block grant system.

Dr. BOGGS. Well, I would agree that there will be certain continuing momentum to begin with because States have gotten into the habit of doing certain things along the lines that Federal funding contingencies have specified. However, as the effect of the 25 percent cutback in Federal funds becomes apparent, and impacts not only on the DD program but on many other programs, the States are going to have to cut corners. And I think there will be considerable difficulty in maintaining advocacy for a group which, by definition, needs complex services over a long period of time. There is great temptation in politics to spread things around among the greatest number of people, and when you have a group that is most disabled and most handicapped and least able to speak for itself, that group is likely to be short changed in this situation.

I think furthermore that we are in the midst now of a systems revolution vis-a-vis this group. We are attempting to move them into new kinds of situations, more enhancing, and the arrest of that process in midstream will be very damaging in the long run, socially.

Many of the unsatisfactory conditions affecting people with DD which we are combating today in our field originated in the Great Depression because during the depression, we had an exceptionally large number of children and proportionately, developmentally disabled children, although we did not identify them specifically at that time. And the retrenchment of programs that were in place at that time as a result of the depression, as a result of the impact on State governments of the unavailability of funds, is something that we have been overcoming gradually in the past 20 years—and we are still at it.

The impact of the withdrawal of the Federal presence from support of programs to deal with these most vulnerable people, if it is allowed to take place, is going to have an impact that we will be still contending with in the year 2000.

Senator WEICKER. Mrs. McClelland?

Mrs. MCCLELLAND. I guess my major concern on this would be, which is why we are speaking on behalf of the extension of the Developmental Disabilities Act, that if "developmental disabilities" is not mentioned specifically in the block grant and the type of services that we as State councils, are involved with—for example, advocating for services for the developmentally disabled and planning—then 10 years down the road, we will find ourselves in a position where it will be used against us. "Well, who says you have to serve the developmentally disabled out of this block grant?"

As a parent of a child with autism, I have known what it is to be on the outside, and to have people say, "Well, we would like to serve your child, but we cannot, because he does not fit into the program. It is listed nowhere that we should serve the autistic."

It is the fear of getting lost in the crowd as to why we would like it specifically kept categorical so that we will have some leg to stand on when people refuse services to the developmentally disabled.

I think Elizabeth went into this, too. When you have a program trying to serve many people with limited funds, it is always the most handicapped that are left out. If I had my choice of serving either a calm, mildly retarded child in a program, or a wild, autistic child who has no speech, I can guarantee you which one of them is going to get the first crack at the services when there are limited funds.

So, that is why I like the developmental disabilities program, in that it has been the impetus to serve those children who are the most difficult to serve, and to let us help people find methods and ways to serve them appropriately.

Senator WEICKER. I think you might even be able to extend your analogy between what you call the wildly autistic child and the slightly retarded child. You can also extend that analogy between those who are in that category and those who are normal, as to where the choices lie, and I think that analogy would continue right up the scale. I agree with you, I think that is one of the difficulties.

You have both been most instructive. I thank you very much for your testimony.

I would hope—and I might say this to all the panelists—I would very much appreciate it if you would write to the committee a short statement that if the administration prevails in terms of the block grant concept, you might set forth any suggestions in the sense of what strings should be attached to the concept, what I referred to earlier as the categorical presence. I am not saying that will be the case, but I would like to have something in my files to respond with as we get into the debate among the members of the subcommittee and the full committee, so that I have something other than the present system and block grant system, this middle ground which I suspect is going to be addressed. I would like to have your ideas on that.

Thank you very much.

[The following material was subsequently received for the record:]

455 Pasadena
St. Louis, Missouri 63119
June 4, 1981

Honorable Lowell P. Weicker, Jr.
United States Senator
313 Russell Senate Office Building
Washington, D.C. 20510

Dear Senator Weicker:

This letter is in response to your request for additional information relating to the Developmental Disabilities Assistance and Bill of Rights Act. As you know, I testified in support of legislation, S.1132, to extend authorizations for appropriations for the Developmental Disabilities Act before the Senate Human Resources Subcommittee on the Handicapped April 30, 1981. At that time, you requested suggestions as to how to maintain the categorical presence of Developmental Disabilities within the block grant concept, should that concept be implemented.

During my testimony, I expressed the concern that persons with developmental disabilities would get "lost in the crowd" should the Developmental Disabilities program be placed within a block grant. As you are aware, with the exception of Developmental Disabilities, all of the programs which are proposed to be included within the Social Services Block Grant provide direct services to their constituency. There will be tremendous competition at the state level for the funds after they are reduced in order to continue those services which are provided under the current categorical programs. It will be difficult for the developmentally disabled to compete against the traditional day care, foster care and other services for the disadvantaged.

It is, therefore, my suggestion that provisions be made whereby the developmentally disabled population is specified as a target group within the block grant legislation. Furthermore, the functions of the protection and advocacy system and the state planning council, i.e., planning and advocacy, need to be identified in the purpose section of the bill so that it will be clear to the state that it can expend federal monies for those purposes.

The provision of federal funds to states without regulations will create a new atmosphere as decisions are made regarding desirable funding options and service priorities at the state level. Without the councils, parents and other consumers will not have a mechanism to impact on other programs and may not be able to have input into the development of state policy, especially with regard to the state's service priorities. There needs to be provisions for (1) both the state planning councils and the protection and advocacy systems and (2) requirements for consumer involvement so that states will continue to perceive the developmentally disabled as a population which needs quality programs and services.

In addition, clarification needs to be provided as to how the protection and advocacy system would be administered. Presently, protection and advocacy is not administered by a state agency. Finally, any proposed block grant legislation should reference the Developmental Disabilities Bill of Rights.

On behalf of the Missouri Planning Council for Developmental Disabilities, thank you for soliciting my input. I sincerely appreciate your efforts to ensure that programs and services are provided for the developmentally disabled. Please let me know if I can be of further assistance.

Sincerely,

Emmy McClelland

Emmy McClelland, Member
Missouri Planning Council for
Developmental Disabilities

EM:sl

cc: Senate Committee on Labor and Human Resources

Senator WEICKER. The next panel refers to the four major components of the act: State planning council, protection and advocacy system, university-affiliated facilities, and special projects.

We have Alice Angney, member of the State of Vermont Planning Council on Developmental Disabilities, and parent of a child with Down's syndrome, who will address herself to the role of councils in each State to coordinate, advocate, monitor, plan, evaluate, and assist in the provision of comprehensive services.

We have Elliot Dober, director of the Office of Protection and Advocacy for Handicapped Persons, in Hartford, Conn., who will address himself to the fact that each State must have in effect a system to protect and advocate the rights of persons with developmental disabilities.

We have Dr. Marvin Fifield, director of the exceptional children's center, a university affiliated facility, who will address himself to the matter of model programs, innovative habilitation techniques and training of personnel.

And we have Bill Copeland, from the University of Minnesota, adjunct professor at the Hubert Humphrey Institute, Special Project of National Significance. He will address himself to the cost analysis of residential and support service programs for persons with different levels of disability in restrictive and less restrictive community settings.

Again, I will repeat that we would appreciate it if you would keep the presentation within the 10-minute mark so we might have a chance for questions, as I indicated earlier.

Please proceed in any way you deem appropriate. I am informed that Senator Stafford wants to be here to introduce you, Alice, and be here during your testimony, so why doesn't some other member of the panel proceed first?

Mr. Dober.

STATEMENT OF ELLIOT DOBER, DIRECTOR, OFFICE OF PROTECTION AND ADVOCACY FOR HANDICAPPED PERSONS, HARTFORD, CONN.; ALICE ANGNEY, MEMBER OF STATE OF VERMONT PLANNING COUNCIL ON DEVELOPMENTAL DISABILITIES, AND PARENT OF A CHILD WITH DOWN'S SYNDROME; MARVIN FIFIELD, DIRECTOR, EXCEPTIONAL CHILDREN'S CENTER; AND BILL COPELAND, ADJUNCT PROFESSOR, UNIVERSITY OF MINNESOTA, HUBERT HUMPHREY INSTITUTE, SPECIAL PROJECT OF NATIONAL SIGNIFICANCE, A PANEL

Mr. DOBER. My name is Elliot Dober. I want to thank you for letting me come before you. I am the director of the P and A Center in Connecticut.

If you have any problem of understanding me, please, Senator, interrupt me at any time. I do not mind at all.

You have an outline of my statement before you.

Senator WEICKER. Yes, we do, and your statement will be included in its entirety.

Mr. DOBER. So I am going to really summarize the way P and A works throughout the country.

There are 54 P and A centers, all types of P and A systems, in government and out of government. They do a variety of things. They protect the rights of individuals who cannot protect themselves.

Approximately 40 percent of our calls come from parents of people who are disabled. Fifty percent come from agencies in the field who need help.

Every P and A works a little differently. The main goal is to protect the rights of individuals, protect the rights of handicapped people who cannot protect themselves.

In Connecticut, if I may, we have one of the finest P and A systems made up of individual case advocacy where we have three advocates who take on a great deal of the calls. We handled almost 2,900 or 3,000 cases since 1977.

The P and A system in Connecticut also has a public information component. Now, when you do public outreach and education, you get more cases, and you get more people calling up. And over the years, there have been a great number of calls, and they have increased over the years.

P and A's also operate a legislative coalition that I am the cochairman of. We coordinate 48 nonprofit agencies. A member of the Easter Seal Society, David Daughtery, is our cochairman.

It is very important to form State legislation so we may have an impact on the State picture.

We have a legal component made up of one attorney, and one part-time attorney.

It should be pointed out to you, that only 2 percent out of all the cases had some kind of legal remedy. This 2 percent is 2 percent of 68,000 cases that all P and A handles throughout the country.

It is also to be pointed out to you that we get in our office, and most P and A systems get in their offices, cases that nobody, no Federal agency, want. We are like the court of last resort. We are

like—nobody wants these cases. And our phone, our system, is going all the time.

Over the 4 years since P and A's have been in effect, I believe that they have played a great role. I believe that we are strong. I believe that we have a lot more to do.

I would also, Senator, if I may, comment on the block grant—or would you like me to save that until later?

Senator WEICKER. Elliot, I do not want to be accused of any favoritism, since we both come from Connecticut. I am going to invoke the 10-minute rule on you, as I would anybody else, so why don't we come to that later, so I can move to the other panelists, and then we will get back to it.

Mr. DOBER. I would be honored.

Senator WEICKER. At this time, Senator Stafford has joined the committee. The reason why you saw me smile, as he came in, he suggested that to be the left of me really did get him into a lot of trouble—he is talking about where he is sitting.

In any event, Bob Stafford, to my way of thinking, is one of the finest Members of the U.S. Senate, and one who has long been involved in the problems that are under discussion here. And believe me, when it comes to the matter of advocacy for those that all of you represent, we have a very fine advocate in Senator Stafford.

Senator Stafford, I understand you are here to comment and also to introduce Alice Angney.

Senator STAFFORD. Thank you very much, Mr. Chairman.

I did come here to introduce Alice, who is to be a witness here this morning, but thank you for your kind words. I do want to say, after having served on the Subcommittee on the Handicapped over the last 10 years on this committee, that I am particularly gratified, and I think the country is particularly lucky that a man of your ability, stature, intelligence, and willingness to be outspoken has undertaken the chairmanship of this very important committee. And I am very happy to be able to continue to serve on this committee under your leadership role.

Senator WEICKER. Thank you.

Senator STAFFORD. Alice Angney of Vermont, of whom we are proud, is the parent of four daughters, the youngest of whom is a developmentally disabled child. Mrs. Angney has been a member of the Vermont Developmental Disabilities Council since its inception in 1970 and is a past chairperson of the council. She is currently the chairperson for the projects review committee and a member of the administrative policy committee for Satellite University Affiliated Facilities. Mrs. Angney is director of special education for the Washington Central Supervisory Union School District in Vermont.

Mr. Chairman, with this description, it is easy to see that Alice is particularly well qualified to testify before this subcommittee, and for the committee, for my State, and for the full committee, I am very happy to have this opportunity to introduce her this morning.

Mrs. ANGNEY. Thank you, Senator.

Mr. Chairman, it is a pleasure to be here. This is an awesome process, and I would be lying to you if I told you that I was not nervous. I would love to move this to my dining room table. I have a feeling I would be much more articulate. It is a subject that I

believe in and could speak on for a long time. But if this morning, I could just highlight for you a couple of things.

I think that with my daughter's disability, what we are facing is lifelong needs in the areas of education, vocational training, employment, housing, recreation, leader activities—in fact, in life support.

Unfortunately, despite Federal and State initiatives, which include the Education for All Handicapped Children Act and the Vocational Rehabilitation Act, there is no program or programs currently available to meet Amy's multiple needs. And it is through such programs as the developmental disabilities program where we can address these needs in the context of a service delivery system.

Please do not misunderstand. I support the legislation I named. But it is not a total solution, and it is not a comprehensive system.

I think that the DD Act has an absolutely marvelous forum for consumers, State agency people, local agencies, providers, and the general public, to do just what the legislation requires—identify service gaps, determine coordination strategies, develop implementation plans, and to monitor those plans. And it is only through this kind of coordination and development of comprehensive plans that we can hope for comprehensive lifelong services for our population of developmentally disabled.

The coordination and planning function that is vested in the council, and the required review of State plans that is also vested in the council offers both me and my daughter, and all individuals who are developmentally disabled, the real possibility that there will be programs and services that will meet her lifelong needs and meet all the developmentally disabled people's lifelong needs.

The council is unique in that it has a requirement for the consumers, State agency people, local agencies and private providers to participate and thus, greatly enhance the planning, the monitoring and the evaluation functions which are vested in the council. Sometimes, I wonder if the Congress had particular foresight 10 years ago, when they enacted the original developmental disabilities legislation; the purposes for which it was designed are so germane and critical in today's economic climate.

It is very easy for me to outline for you some of the projects that we have done in Vermont. For instance, we did a Vermont infant screening program, or a residential manager's training program. They have substantial, documentable outcomes, all of which are available to you. But the part of the council that is not so easily illustrated, and what I feel is the very essence of the DD formula, the basic formula grant program, is how it has resulted in gaining access for persons who are developmentally disabled to the generic service systems; how the council actions have increased public awareness for the needs of the developmentally disabled individual, and how their activities have resulted in improved service, reduction of duplication, better data collection, compatible intake systems, and development of the guidelines for quality services.

Our State council and the State agency members on our council have reviewed their programs and their budgets, and we do this annually. We have found that much better decisions are made with

the councils are systematically asking the questions, how much is being spent, what for, and why.

We are basically a systems change and a comprehensive systems integration system, and these things are very necessary as we face scarcer resources.

Consumer involvement in systems change is crucial. The consumer provides the nonbureaucratic view, and I think by doing that can save valuable time and costly mistakes.

It was pointed out to me when I got into the developmental disabilities field 10 years ago that this legislation provided a relatively small amount of money, but its impact would be worth many times that investment because its purpose was to increase the ability of the ongoing service system. And I think that that has happened, I think that that is the crux of what we need to continue to do. We have to review ongoing service systems and to assure that the moneys are being spent for the population, the developmentally disabled, that we are most concerned with.

We need to review the systems for coordination, nonduplication, and efficient and quality services.

I have said that it seems to me that a time when we have put 10 years into a program to get it to function, to make other programs function more effectively and more efficiently, to utilize the dollars that we have in a coordinated fashion, and provide mechanisms for systems change, that it would be a crime to throw that out at a time when we are at a juncture in the provision of social services, and when this legislation addresses the needs of the developmentally disabled so very, very well.

Thank you, Mr. Chairman.

Senator WEICKER. Thank you very much, Alice.

[The prepared statement of Mrs. Angney follows:]

TESTIMONY

O N

THE DEVELOPMENTAL DISABILITIES ASSISTANCE

and

BILL OF RIGHTS ACT

Respectfully Submitted

to

The Senate Subcommittee on

The Handicapped

Witness:

Alice Angney
Consumer Member, Vermont Developmental Disabilities Council

Mr. Chairman and Members of the Subcommittee, it is a pleasure to be here to speak on behalf of the Developmental Disabilities Program. My name is Alice Angney. I have four daughters; our youngest daughter, Amy, has Downs Syndrome.

I have been a member of the Vermont Developmental Disabilities Council since its beginning ten years ago. During that time I have had the honor of serving as the Chairman for the Council from 1971 to 1974 and 1976 to 1978. I am currently the Chairman for the Project Review Committee. I have served on the Vermont Protection and Advocacy System Advisory Board and I am currently on the Vermont University Affiliated Facilities Satellite Administrative Policy Committee.

My daughter's disability is such that she will have lifelong needs in the areas of education, vocational training, employment, housing, as well as recreation and leisure activities. Unfortunately, despite both federal and state initiatives, there is no program or programs currently available to address Amy's multiple needs. The Education for All Handicapped Children Act (PL 94-142) has not solved all the educational problems of developmentally disabled children nor has Vocational Rehabilitation solved the training and employment needs of developmentally disabled adults. Do not misunderstand. I support both pieces of legislation and consider them <u>vital</u> parts of the system for individuals for developmentally disabled. However, the legislation alone does not guarantee the coordinated continuum of services required by the developmentally disabled. One of the greatest challenges that we all face is influencing the generic service systems to fill the gaps in service which now exist.

In the Developmental Disabilities Act, you provided for a marvelous mechanism to address the developmentally disabled individual's needs in the context of the service delivery systems. The Developmental Disabilities Councils

provide a forum for consumers, state agencies, local agencies, providers and the general public to identify service gaps, determine coordination strategies and develop implementation plans. It is only through this kind of coordination that there is any hope for the development of comprehensive and coordinated lifelong services such as those needed by my daughter. Let me give you an example. If my daughter were to have available appropriate vocational training and there was not concurrently job development and follow along services to assure the opportunity for job placement and maintenance, we have wasted the vocational training. More tragically, we are wasting a human life, and may even force people unnecessarily back into expensive institutions. When systems develop in isolation, the potential for this to happen is great. The coordinated planning function plus the required review of state plans vested in the State DD Councils offers me and my daughter, as well as all individuals who are developmentally disabled, the real possibility that this kind of lopsided development will not occur.

The uniqueness of the Council, with the requirement for consumers, state agency, local agency and private provider participation, greatly enhances the planning, monitoring and evaluation functions vested in the Council.

I have wondered if the Congress had particular foresight when you originally enacted the Developmental Disabilities legislation. The purposes for which it was designed are so germane and critical in today's ecenomic climate.

Such things as the Vermont Infant Screening Project which was developed as the result of Council identification of the need for a statewide early screening device for high risk infants are easy to report to you. The Council worked with the Vermont Department of Health and private providers to plan and implement a screening program with follow up early intervention for developmentally disabled infants. This program was developed, piloted, monitored, evaluated, redesigned as a result of evaluation and finally

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totally integrated into the State Health Department Budget.

Equally easy to tell you about is the Residential Manager Training Program. When community residential programs were really beginning to develop, it became apparent to the Council that training was necessary for the staff if we were going to have quality programs for the individual who is developmentally disabled. In this case it was the Department of Mental Health who worked with the Council to develop such a program and in cooperation, test monitor and evaluate it. This program has been integrated into the Department of Mental Health's training budget.

These are two examples of many such cooperative system building that the Council has been instrumental in.

What is not so easy to illustrate but what is the very essence of the DD Basic Formula Grant Program is how it has resulted in gaining access for persons who are developmentally disabled to generic service systems; how Council actions have increased public awareness of the needs of developmentally disabled individuals; and how Council activities resulted in improved services, reduction of duplication, better data collection, compatible intake systems; and the development of guidelines for quality services.

The Council, with the State Agency members, have reviewed the programs and budgets of the member agencies. We have found that better decisions are made when it is known that the Council is systematically asking the questions; how much is being spent; what for; and why?

System change and comprehensive system integration are necessary as we are faced with scarcer resources; and at the same time a commitment to the developmentally disabled citizens as they are not only the "truly needy" but perhaps the most needy of all, due to their severe impairments.

Consumer involvement in systems change is crucial. When made a part of the process, consumers can save valuable time and costly mistakes. It is my experience that the consumer provides the non-bureaucratic view to system

There have been many occasions when consumer and agency people have worked out effective and innovative solutions around the DD Council table, but that is just a bonus. The real benefit and the one I admire most in the legislation is the requirement for systematic planning.

One of my first introductions to the Developmental Disabilities Act highlighted the uniqueness of this legislation. It was pointed out to me that this legislation provided a relatively small amount of money, but its impact could be worth many times that investment because its purpose was to increase the ability of ongoing service systems. I was told it was out job as Council members to review ongoing service systems to assure that all monies intended for developmentally disabled individuals were being used for them. Additionaly, we were to review delivery systems for coordination, non-duplication and efficient, quality services.

I have spoken to you of the Basic Formula Grant Section of the Developmental Disabilities Act because as a consumer member of the Council, this is the area in which I have participated th most. However, I do want to acknowledge the major role that the Protective and Advocacy System, the Satellite University Affiliated Facilities Program and Special Projects Grants have played in improving the lives of individuals with developmental disabilities.

Our Council, state agencies, private providers, and persons with developmental disabilities have benefitted from a Project of National Significance, the Developmental Disabilities Telecommunications Project. (HEW Grant No. 54-P-7132/2/2-01.) This project demonstrated applications of telecommunications technology which truly are "of national significance". The principal project contractor was the Alternate Media Center at New York University. Publications evaluating the project have been produced by the Institute for the Future, Menlo Park, California.

In Vermont the project promoted greater cooperation and coordination of effort among the Council, University Affiliated [illegible]

University of Vermont, Agency of Human Services, private providers, and voluntary associations serving persons with developmental disabilities. Specific applications included audio conferencing, computer conferencing, and use of micro or "home" computers by persons with developmental disabilities.

Our experience in Vermont with this particular project of National Significance convinces me that the federal government must continue to encourage this kind of imaginative leadership at the national level. The resources needed to investigate the w a y s telecommunications technology can benefit Councils, UAFs, providers, and consumers is simply beyond the capability of individual states.

The hope for a productive life for my daughter, Amy, and for all developmentally disabled individuals, has been improved as a result of the Developmental Disabilities Act.

At this juncture in the provision of social services, this legislation is unique in that it addresses efficient, effective non-duplicative provision of service, includes local and state participation in the planning and coordination activities and increases accountability to the taxpayer. I urge your continued support of the unique and effective legislation.

I wish to thank you, Mr. Chairman, and all members of this Subcommittee for this opportunity to testify.

Senator WEICKER. Dr. Fifield, of Utah, please proceed at this time.

Dr. FIFIELD. Senator, in the interest of time, Dr. Mike Morris suggested that I do not use the slides that I brought. I accept his suggestion for I realize the problem that we have with time. However, it will affect the presentation because it was designed to be presented with slide.

Senator WEICKER. Well, you made the effort to do something here. How long is the presentation, Dr. Fifield?

Dr. FIFIELD. It is 10 minutes.

Senator WEICKER. Why don't you go ahead and make your presentation, then.

Dr. FIFIELD. I think there is a need for visuals.

Senator WEICKER. You also have slides with your presentation, do you, Mr. Copeland?

Mr. COPELAND. Yes.

Senator WEICKER. Well, why don't we proceed right away with Dr. Fifield, then?

Dr. FIFIELD. Senator, I am very honored to be asked to testify on behalf of the needs of the developmentally disabled, and specifically the university affiliated facilities program.

I am going to base my remarks on two premises. The first premise is that the developmentally disabled are a distinct and unique population. Dr. Boggs has testified to this earlier. By definition, the developmentally disabled have more than a single handicap. They have multiple handicaps, and their needs are multiple. Therefore, they require the help of many different disciplines. Furthermore, the developmentally disabled's problems increase in severity as they get older. Senator Weicker, you yourself commented on this fact. A developmental disability is a disruption of the developmental process, and such handicaps continue in severity and complication unless they are treated. This clearly sets them apart as among the most needy of our population.

The second premise of my remarks is that the university affiliated facility is an important link in improving the lives of the developmentally disabled. We spend billions of dollars on service programs. We spend significantly less on research, approximately 1 percent. We spend even less on applied research, conducted in realistic settings, in which we can evaluate effectiveness and cost. The mission of the university affiliated facility program is to bridge that gap.

There are three basic goals to the program. The first basic goal is interdisciplinary training. No service program, regardless of the funding, can be any better than the training of the people who provide that service. It is basically people who make the difference. An investment in training is a seed money investment, where payoffs pyramid each year of service.

The second goal of the university affiliated program is the provision of exemplary services. The UAF service programs are designed to represent the best practices, the most cost-effective and result-effective techniques that we know. Other components of exemplary service include continued evaluation and replication of successful practices.

The third goal is dissemination of information to consumers, policymakers, and providers. Without proper information dissemination, we lurch around in a trial and error method. it is poor dissemination that results in duplication and redundancy of effort.

There are, of course, other centers that deal with problems of the handicapped. These include the research and training centers, rehabilitation centers, and the engineering centers. But these centers have more restricted missions. It is the university affiliated facilities program that addresses this combination of research, training, exemplary service, and dissemination.

The Exceptional Child Center at Utah State University is 1 of the 46 university affiliated centers located at major universities across the United States. The Exceptional Child Center is a regional center. It serves four States, Utah, Navada, Idaho, and Wyoming. In addition, we have helped develop two satellite programs, one in Montana and one on the Navajo Reservation in Arizona. These satellite centers extend service programs to unserved areas.

The special mission of the Exceptional Child Center is to serve developmentally disabled people in rural and remote areas. Let me briefly describe one of the exemplary programs that we are conducting. The cooperative extension program for the handicapped has been initiated in rural Utah and a number of areas in surrounding rural States. This program is funded primarily by the U.S. Department of Agriculture, and follows the cooperative extension model. We utilize local paraprofessional, train them as case managers and advocate for the developmentally disabled. The Exceptional Child Center provides backup services. This includes, first, instruction materials for parents to use; instructional materials designed for siblings, grandparents, and volunteers to use. These materials are provided in instructional packages to help improve the independent living skills of the handicapped child. At the present time, we have over 150 instructional packages that have been developed, each addressing a specific learning task which will improve the independence and the functioning level of the handicapped individual.

The second type of backup service is consultation. This is provided primarily by telephone. At least weekly, we make contact with every participant in the program, to monitor their progress and make adaptations to their unique needs. Communication is a two-way process between the area and the Exceptional Child Center. The success of this program is fantastic. Our data indicated it is a very cost-effective method for serving the handicapped in rural areas.

I would like also to explain briefly the service process, the typical procedures in which children are served at the Exceptional Child Center.

Generally, referrals come to us from one of the State service agencies. Over 60 percent of all the referrals to the Exceptional Child Center come from service agencies. The cases referred are usually very complicated. For the most part, they are cases that the State agency is experiencing difficulty in working up, cases that need interdisciplinary evaluation and programing.

The Exceptional Child Center is therefore responsible to: (1) Establish a definite diagnosis. This may include medical diagnosis,

psychological, language, and so forth. (2) Prepare program recommendations for treatment or intervention. These programs are designed specifically for the handicapped person who is being evaluated. (3) In addition to the service to the client, we provide training to university students, to teach them the techniques that are involved in diagnosis and programing. (4) We also provide technical assistance to the referring agency. This expands their knowledge to better handle similar cases in the future.

The next series of four slides is a success story. It covers a period of 9 years of a boy who entered into our program. I think you can see the change that has occurred in this boy. He left our service 2 years ago, and is currently living in a group home, working in a sheltered workshop and making a good adjustment to life.

The UAF's and research centers maintain regular communication through an electronic message system. With this system, we can go directly to many of the most knowledgeable people in the world when we have questions about a diagnosis or a treatment program. Recently, this information network was linked to the State Developmental Disabilities Council. Thus, this completes the communication link that we need between research centers, controlled application and service agency.

The relationship between the Exceptional Child Center and our State Developmental Disabilities Councils is extremely close. We have daily contact with the councils we work with. The DD Councils serve as a forum of professionals and concerned citizens which meet to consider problems of the developmentally disabled, to advocate and, when necessary, to intercede on their behalf. The staff of the Exceptional Child Center and the other UAF's serve both as a part of that forum and as a resource to the council.

We might pause and ask, what has been the impact of the UAF program on the handicapped. There is a great deal of data to answer this question. Much of this data has already been provided to the committee. Other data in answer to questions you may have we would be happy to provide. In the interest of time, let me respond to two significant data points.

In fiscal year 1979—this was a typical year—over 58,800 professionals received interdisciplinary training in the UAF network. During this same year, direct services were provided to over 68,200 clients and their families. Although I do not know the depth of training or the severity of the problems of clients served at each of the UAF's, at the Exceptional Child Center, the training students receive is supplemental to their regular training in their respective disciplines. For many students, interdisciplinary training at the UAF provides specific skills and strategies to serve the unique problems of the developmentally disabled as an area of speciality. Furthermore, the clients referred and served are, for the most part, the most complicated and difficult cases. When one considers the depth of training and service provided by UAF's the impact of the program is very significant.

Funding to the UAF programs comes from a variety of sources. However, the core administrative support for UAF's is provided by the Developmental Disabilities Act. It is these funds that give the UAF program its focus and enables each center to respond to the

programmatic needs of the handicapped on a national and a regional basis.

Many of the problems that face the handicapped are national in nature—training, research and dissemination must be addressed at a national level. Historically, States have not assumed this responsibility and it is unlikely they will assume it in the future.

I am concerned with the plan to return large amounts of human services money to the States for distribution. Most States are not prepared, nor are they in the process of preparing to handle this type of funding. To the contrary, many States and local agencies are entrenching. They are cutting back, eliminating staff and administrative personnel. Thus, they will be even less prepared to handle block funds if the current proposal is thrust upon them.

The repeal of the Developmental Disabilities Act, Public Law 94-142 and other legislation that has been enacted on behalf of the handicapped will not result in a significant savings. Without appropriate treatment and intervention, the problems and the difficulties faced by the developmentally disabled will increase in severity and in complexity. Costs, both in terms of money and in human suffering, will increase and be passed on in less humane, less effective and more costly programs in the future.

I urge the reenactment of the needed legislation with appropriate safeguards to insure that those who need the services do indeed receive the services they need. Further, I urge that programs of national interest, including our research, our training, and our dissemination efforts, be continued with adequate safeguards to insure their integrity and quality. I thank you.

Senator WEICKER. Thank you very much, Dr. Fifield.

[Responses of Dr. Fifield to questions submitted by Senator Randolph follow:]

Questions for Dr. Marvin Fifield from Senator Randolph

Question No. 1

You stated that in 1979 that over 46,000 professionals received interdisciplinary training in UAFs. For the record, would you please provide the Subcommittee with the number of days of training (on the average) that each professional received.

Response

The figure "46,000" professionals receiving interdisciplinary training was taken from a report of only the UAFs that received administrative and core support from the Administration on Developmental Disabilities. Furthermore, this figure only represents university students (preservice trainees) in the UAFs. This figure does not include the well over 100,000 individuals who received inservice or outreach type training at UAFs (Henney, 1981). The UAF interdisciplinary trainees averaged over 40 hours (5 days) of interdisciplinary training. The inservice or outreach trainees provided in short courses or special workshops received on the average of over 4 hours of interdisciplinary training.

Questions No. 2

With reference to the 46,000 professionals trained, what proportion of that interdisciplinary training would have been paid for out of Developmental Disabilities funds? What were the other sources of funding?

Response

Very little, if any, of the interdisciplinary training provided to the 46,000 professionals during 1979 was paid for out of Developmental Disabilities funds. Direct training is not an approved expenditure for Administration on Developmental Disabilities core support to UAFs.

The largest single block of financial support for interdisciplinary training came from Maternal and Child Health. MCH provided funding for fellowships and for special purpose workshops to approximately 21 of the 46 UAFs. The interdisciplinary training provided from MCH is very systematic long-term training and is directed to health and allied health professionals serving the handicapped.

Other sources of support for UAF provided interdisciplinary training included Office of Special Education, Personnel Preparation funds; Rehabilitation Service Administration funds for R&T centers, short-term and long-term rehabilitation training; Title XX and Title XIX.

A great deal of the training provided in UAFs is paid for through specific contracts written and submitted to state, local and federal funding agencies. The funding agencies specify the length and type of training to be provided in the target population.

The Developmental Disabilities core support funds provides the administrative and core support that makes it possible for UAFs to meet this training need. Without administrative funds, UAFs could not have the core staff to respond to the training requests of service agencies and the program would lose its integrity to provide the quality of interdisciplinary training needed.

Question No. 3

Of the 46,000 professionals trained, how many were trained to work with adult developmentally disabled individuals?

Response

In many respects, training to provide services to the adult handicapped is not greatly different from training to provide services to children. Many skills, particularly diagnostic and prescriptive programming skills,

are virtually the same. Thus, all interdisciplinary trainees are prepared to work with the full age range of the DD population.

Some differences occur at different age groups when direct services are being provided, i.e., adult handicapped need greater emphases on rehabilitation, independent living skills, life support skills, survival skills, etc. Professionals receiving interdisciplinary training to provide such services include teachers, rehabiliation personnel, social workers, case managers, legal advocates, etc. The need for professionals to provide services to adult handicapped is a priority of the Administration on Developmental Disabilities and has received special attention in the UAFs. It is estimated that approximately one fourth of all the people receiving professional training in UAFs during 1979 had some training directly geared towards the adult developmentally disabled. Funding for this training was provided by the Administration on Developmental Disabilities, services and special project funds, Rehabilitation Service Administation, Title XX and Title XIX.

Senator WEICKER. Bill Copeland.

Mr. COPELAND. Thank you, Senator.

I am Bill Copeland from the University of Minnesota, the Hubert H. Humphrey Institute of Public Affairs. I specialize in human services financing for State governments and for the Federal Government.

I am here today as a recipient of an ADD grant of national significance. Our grant supports technical assistance to the States in developing community services for the developmentally disabled and phasing down institutional beds. The grant is in its third and final year.

During the time of the grant, we worked with about 20 States, some with great success, and some with none whatsoever. From our work with the States and our statistical work on a national policy model of the mental retardation and developmental disabilities industry, we have also been able to supply the Federal Government with technical assistance on the fiscal effects of Federal deinstitutionalization policy.

We have included some of these as appendices to our testimony. There, we provide analyses of who is getting cared for where, what it costs, and what the sources of funding are. Our estimates differ somewhat from the estimates you heard this morning from the administration.

Our work starts from the observation that Federal programs and State budgeting practice are extremely fragmented. The total system of care for the MR/DD people is rarely considered. We look only at one thing at a time—institutions, nursing homes, home care, or day activity programs—but never at all the services across

the continuum of care. And we do the same thing on budget. We look at DD funding alone, or medicaid alone, or medicare alone, or SSI, or title XX, State or county funds, ignoring the fact that all of these funds go to support what is implicitly a single MR/DD system, in a State.

Now, the public costs for MR/DD in 1979 were about $10.7 billion; Federal, $4.2 billion; State, $6.5 billion. Medicaid, title XX, SSI, and SSDI were the chief Federal supports.

In general, programmatic theory and most court decisions say that incentives for client movement should be from the least normalized to the most normalized care opportunity. However, the fiscal incentives, as the States perceive them, especially in medicaid, imply that the movement should be toward the least normalized, most restrictive forms of care and treatment.

What we do in our technical assistance project is to show the States how these incentives are now operating, and how they may be changed toward a normalized, community-oriented system of care. We do that by first showing the State it is working with a linked set of care opportunities, instead of a fragmented, unrelated bunch of funding accounts. Then we take into consideration all sources of funding. Then we develop a budget across the whole continuum and contrast alternative approaches to providing care in institutions, in the home, in small ICFMR's, and so on.

And this is an important point here because of some recent opinions that have been given that deinstitutionalization is massively costly. As it turns out, for virtually every State we have looked at and in our national model, deinstitutionalization is the cheaper, less expensive way to go, holding program constant or even improving it. In fact, what it means is that in contrast to what we do now year by year, if we went into a speedier deinstitutionalization approach, we would save approximately $3.5 billion or more by 1985 by deinstitutionalizing. Much of that would be Federal savings. And that contrasts with the savings that would be received under the proposed caps on medicaid and on the social services grants. The savings to the Federal Government under those caps in 1985 would be about $750 million in the MR/DD area—as contrasted with over $3.5 billion if we have designed-in cost control.

To give you an example of what happens in an individual State when you either do or do not deinstitutionalize, in 1985, Pennsylvania will be spending, if it holds to its 1980 configuration of care, about $580 million in its own funds. If it goes to a deinstitutionalization approach of the kind now being planned by the State, going from about 7,300 beds down to 4,000 beds in their State institutions, among other things, they would save about $130 million in State funds—this assumes a Federal medicaid cap.

At present, a number of States have recognized how they can go into a continuum of care planning. And such States as Illinois, Vermont, California, New York, Massachusetts, the District of Columbia, Minnesota, and North Dakota have either set themselves to begin or have already gone down that road. The State of Illinois, for example, with the aid of DD Council planning money, has come to the point where it has completely restructured its appropriation

plans for the next 5 years for their entire mental retardation agency.

In the interest of time, I will not give any specific suggestions on policy redirection; they are, however, in my testimony, given the contingencies of what happens in the upcoming budget discussions.

I should note, in conclusion, however, that while the States have had considerable difficulty in integrating and pulling together currently fragmented services, what exists now is certainly not all that bad.

We do have an emerging national policy and State policies toward MR/DD programs that have just begun to coalesce. That is, the States can now see the next steps in the process of developing a care system which meets most of the national goals. Before the States could do that, there had to be implicit continua of care pretty much in place, with some principled guidance by national policy. Thus, title XX required the States to concentrate on the poor and the near poor, through the so-called 50-percent rule. The newer parts of the Rehabilitation Act required the States to stop creaming and to concentrate on the severely handicapped. The DD Act and 94-142 actually moved State MR agencies and school systems toward the "least restrictive habilitative environment", and Public Law 96-272 embodied similar ideas for children in trouble.

Now, I am not sure in the absence of national policy guidance and some fiscal and regulatory incentives whether such policies at State and local levels would be continued. However, we do know that if national legislation is passed now which effectively deletes the principles of equitable allocation and behavioral incentives that are now incarnated in these laws, it is clear that the Congress will have essentially accepted the philosophy that domestic programs and especially human services programs are of no concern to the Federal Government and are, to quote the 10th amendment, "reserved to the States respectively."

Thank you.

[The prepared statement of Mr. Copeland and responses to questions submitted by Senator Randolph follow:]

TESTIMONY

OF

WILLIAM C. COPELAND

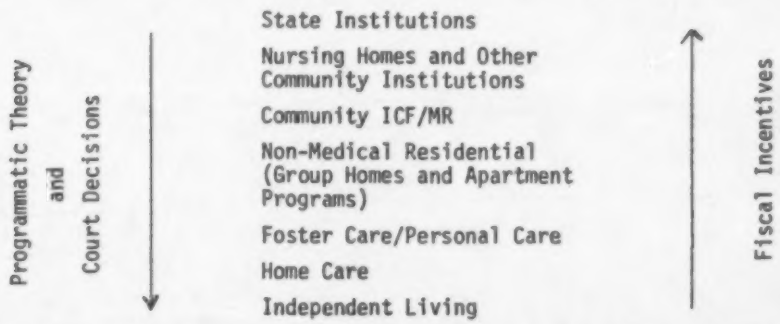
Mr. Chairman and Members of the Subcommittee. My name is Bill Copeland. I am an Adjunct Professor of Public Affairs at the University of Minnesota's Hubert H. Humphrey Institute. I am also President of Seneca Corporation in Minneapolis.

I am here today as a recipient of a Developmental Disabilities Project of National Significance Grant. Our grant, which supports technical assistance to the states in developing community services for the developmentally disabled and phasing down institutional beds, is in its third and final year. During the time of the grant, we have worked with about 20 states, some with great success, some with none.

From our work with the states, and our statistical work on a national policy model of the mental retardation and developmental disabilities "industry," we have also been able to supply the Federal government with technical assistance on the fiscal effects of Federal deinstitutionalization policy.*

Our work starts from the observation that Federal funding programs and state budgeting practice are extremely fragmented. The *total* system of care for the mentally retarded and developmentally disabled is rarely considered. We look only at one thing at a time, institutions, or nursing homes, or home care, or day activity programs -- but never at all services at once. Further, we never look at the total budget for all MR/DD, across the whole system. We look at DD funding, or Medicaid, or Medicare, or SSI, or Title XX, or state funds, or county funds -- ignoring the fact that *all of these funds go to support what is implicitly a single MR/DD system, in a state.*

Consider what the system looks like, in any individual state. We have a group of care facilities which run roughly from most restrictive to least restrictive, from most expensive to least expensive, from most normalized to least normalized. They are:



* A report on our national estimates of persons served, by level of care, and costs of care for the nation, by source of payment, as well as our model analysis of the fiscal effects of different Federal policies, is included as appendices to our testimony.

In general, programmatic theory and most court decisions say that incentives for client movement should be from the least normalized to the most normalized. However, the fiscal incentives, as the states perceive them -- especially in Medicaid -- imply that the movement should be toward the least normalized, most restrictive forms of care and treatment.

What we do, in our technical assistance project, is to show the states how those incentives are now operating, and how they may be changed, toward a normalized, community-oriented system of care.

We do that by:

- Showing a state that it is dealing with a linked set of care opportunities, instead of a fragmented, unrelated bunch of funding accounts. That is, the state has an implicit continuum of care which it must manage as an explicit continuum.

- Showing a state that it must take *all* sources of funding into consideration, if it is to have a normalized system. Thus, the state must deal not only with Medicaid and Title XX, it must also be aware of and be prepared to deal with the budget implications of SSI, OASDI, Medicare, Child Welfare funds, Vocational Rehabilitation funds, and other sources of funding.

- Showing a state that, if it budgets across the whole continuum, for funds from all sources, and if it develops a plan for speeded-up transfer of MR/DD persons out of institutional beds into community and home-care, it can finance the MR/DD system at a lower cost than would have been the case, if historic trends of deinstitutionalization in the state had continued.

We can do this because the current system of care in most states puts a heavy concentration of money, both Federal and state, in institutions. What evidence we have indicates that good programming in institutions is much more expensive than good programming in the community. Therefore, despite the fears of some that deinstitutionalization will result in massive incremental costs, it can be shown that deinstitutionalization is the only way to maintain a good program *and* hold down costs.

In Pennsylvania, for example, holding to the configuration of care slots available in 1980 would result in a total MR/DD non-Federal system cost of $583 million in 1985, if the proposed Medicaid cap is assumed. Developing a community care system further, and phasing down from 7,300 state institutional beds today to 4,000 beds in 1985 would lead to a total non-Federal system cost of $450 million. This compares to a non-Federal system cost in 1980 of $503 million in Pennsylvania (using 1985 dollars).

The total cost of the national publicly-supported system for MR/DD in 1985, if we radically deinstitutionalize, would be *at least* $3.5 billion less than if we simply followed historic trends, thus reducing the rate of inflation in the MR/DD sector by about three points per year. Thus, it can be shown that designed-in cost containment, through continuum of care planning, is the most effective fiscal control -- and that effective fiscal controls are harmonious with adequate, normalized care programming.

At present, a number of states are starting or are well into the continuum of care planning and budgeting process. Illinois, Vermont, California, New York, Massachusetts, the District of Columbia, Minnesota, and North Dakota are among those states that have gone into the process. Detailed reports on two states -- California and Colorado -- and a report on how we evaluate our own performance in working with states -- are included as appendices.

Where can the Federal government assist this process? There are a number of places where that can happen:

1. Medicaid policy redirection.

   A. If the proposed Medicaid cap and block grant approach does not pass.

      Federal policy should be restrictive on institutional funding (or provide incentives to phase down institutional beds) and, simultaneously, open up funding for small ICF/MR's (and restructure portions of the program), day activity programs, staffing for non-medical programs (even small ICF/MR's are too expensive and intensive for some classes of persons still needing supervision), and case management systems for care continua. MMIS requirements should be redesigned to allow for total cost MA information for each major target group (Aging, MI, MR/DD), by location of service. Place the DD Act language on "least restrictive habilitative environment" in the MR-related portions of Title XIX.

   B. If the proposed Medicaid block grant and cap do pass.

      Medicaid funding for persons with MR/DD diagnoses should be separated from the rest of Medicaid costs, with the states allowed complete flexibility to spend the funds within the continuum of care. This should be considered the first step, with all Federal funding eventually bundled into a Federal-state capitation-oriented MR/DD continuum of care program. This program should be considered a pilot of similar programs for mental illness and aging programs. MA research should examine the flows of those in each target group population of risk into, through and out of the care continuum, as a function of supply availabilities.

2. Policy redirection in HHS/OHDS.

A. If the proposed social services block grant does not pass.

Restructure and simplify the DD Act to put the state and other grant money into a few areas where it will do the most good: Continuum of Care Design and Management; P & A for independent protection of client rights; UAP, as the designated training instrument, developing programs for the continuum of care (e.g., behavioral management training for institutional transition teams, ICF/MR managers, and day activity program persons). The only state DD plans should be in state health prevention budgets and in continuum of care development.

B. If the proposed social services block grant does pass.

Restructure OHD budget into care-system development groups for Aging (this remains within the AOA budget), MR/DD, Mental illness (this might affect decisions on NIMH future budget), Child Welfare populations, physically handicapped populations, and working poor and single-parent family programs. Each grouping would be responsible for research (oriented toward care-system development in each case), training (which would be directly in support of overall care-system management and needed manpower in levels of care in each continuum of care or care system), development of exemplary service programs, and technical assistance to the states in program development and implementation. A last task is the representation of target-group program and program financing needs to the generic programs (e.g., HUD Sec. 8, Ag., HCFA, Social Security). This, as the experience of our project has shown, is an extremely important function. Each target-group-oriented grouping in OHDS should be responsible for all functions for "its" target group, except for financial management and related functions. In that way, both HHS and Congress have better focus and accountability.

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I should note, in conclusion, that -- while the states have had considerable difficulty in integrating and pulling together currently fragmented service systems -- what exists now is certainly not all that bad. Over the last 15 years, we have had an emerging national policy (and state policies) toward MR/DD persons that have just begun to coalesce. That is, the states can now see the next steps in the process of developing a care system which meets most of the national goals. However, in order for the states to do that, there had to be implicit continua of care pretty much in place, with some principled guidance by national policy. Thus, Title XX required the states to concentrate on the poor and the near poor, for self-sufficiency and independence-of-life purposes (i.e., the Title XX goal structure and the "50 percent rule"); the newer parts of the Rehabilitation Act required the states to stop creaming and concentrate on the severely handicapped; the DD Act and 94-142 actually moved state MR agencies and school systems toward the "least restrictive habilitative environment;" and P.L. 96-272 embodied similar ideas for children in trouble.

Whether, in the absence of national policy guidance, and some fiscal and regulatory incentives, such policies at the state and local levels would be continued is unforeseeable. However, if national legislation is passed now which effectively deletes the principles of equitable allocation and behavioral incentive now incarnated in these laws, it is clear that the Congress will have essentially accepted the philosophy that domestic programs, and especially human services programs, are of no concern to the Federal government and are to be, to quote the 10th Amendment, "reserved to the States respectively."

APPENDICES

A The National MR/DD Continuum of Care: Number of Persons and Costs

B Medicaid Funding for the Continuum of Care for MR/DD Persons- A Policy Memo

C Refinancing and Reforming the California MR/DD System

D Analysis of Colorado MR/DD System -- 1981-2 and 1984-5: An examination of fiscal effects of current departmental plan and a more heavily community-oriented plan, under Federal funding alternatives which include current Medicaid funding approaches and a "capped" approach of the type now being proposed by the National Administration.

E Technical Assistance: Its Definition and Evaluation

(Note: In the interest of economy, the appendices mentioned were retained in the files of the committee where they will be available foe research upon request.)

REPLY TO SENATOR RANDOLPH'S QUESTION

This note is in response to the question raised by Senator Randolph concerning the testimony of William C. Copeland on April 30, 1981 before the Subcommittee for the Handicapped.

Question:

You stated that "deinstitutionalization is the only way to maintain a good program *and* hold down costs" and that "good programming in institutions is much more expensive than good programming in the community." As you know, in some instances, individuals have been "deinstitutionalized" but have not been provided supportive services in the community. In developing your cost figures, what kinds of services and support did you assume in your cost estimates for a deinstitutionalized population? What kinds of services and support did you assume for an institutionalized population?

Summary Answer:

Costs for service to persons with the same level of handicap are 20 to 80 percent less in the community than in the institution:

1. Where *full-cost* accounting of all residential, generic, and related services is conducted at all levels of the continuum of care; and

2. Where institutional costs are projected to be those required under ICF/MR regulations as a condition for Federal reimbursement; and

3. Where community services are projected to conform to the best practices of the various states (i.e., exemplary models) for each level of care.

A discussion follows.

Discussion:

It is clear that there can be socially irresponsible deinstitutionalization of the developmentally disabled. Although the situation is not as bad as it is in the chronically mentally ill area, it can be shown that a number of states have transferred DD persons from state institutions to nursing homes (SNF's/ICF's) in which little or no active treatment is being provided. Further, it can be shown that many DD persons end up in "no-service" board and care situations which really amount to mini-institutions (or medium-sized ones) in the community.

We have not included such situations in our own calculations of the relative and total costs of institutional and community services. Rather, all of our calculations recognize the full costs of running good programs, and the assumption is made that these costs vary with the needs of persons with differing levels of behavioral adjustment, ambulatory, and other self-care -- and related -- functional skills. This assumption is made at all levels of the continuum of care. Thus, if a person is to remain in an institution, and the state is to get MA reimbursement for ICF/MR care, we include the total costs of care, including those arising from the need to renovate (in compliance with the ICF/MR regulations) and to upgrade staff. If a person is to remain in a nursing home, we add in the costs of related medical care and active treatment (which is generally not being provided now). If a person is to be in an ICF/MR in the community, we add in the costs of related medical care, day programming (day activity or education), supportive social services, case management, and

transportation services. Similar adjustments are made for the non-medical living arrangements -- personal care, specialized foster care, home care, and semi-independent living.

Further, the program of services selected at each level of care is defined and priced to meet the level of service provided in exemplary states (e.g., community ICF/MR's in Minnesota, small group home and apartment programs in Massachusetts, and family subsidies in Minnesota and Connecticut).

When this kind of full cost accounting for *all* services needed at the different levels is conducted for the continuum of care, the costs of community-based programs will range from 20 to 80 percent of the costs of state institutional programs, when type of patient is the same. This has been the pattern in all of the states we have studied. We should note that there are studies which propose that the total cost in the community is as great as in the institution. Even these studies, however, note that the quality of services in the community appears to be superior to that of institutional services.

We recognize that the needed changes changes cannot be made precipitously. But we do assume -- on the basis of our experience -- that a state should be able to restructure its present system along continuum-of-care lines over a five-year period. (A number of states have already restructured their community and residual institutional care programs in this way within a five-year time span, with remarkable results.)

Using our computerized model, we start with the current costs of programs and distributions of persons in a state, and then simulate its reform over time, in a number of different ways, according to estimates by state officials on what they think their targets should be one, two, three, four, five, etc. years from now. We begin by assessing what it will cost the state, if it merely upgrades services to meet the Federal requirements for MA reimbursement of institutional care, maintains its current institutional caseloads, and does little or nothing to develop community, independent living, and home care services. This "baseline" strategy is then compared with strategies in which institutions are phased down, at various rates, and community services are added to take their place.

In all comparisons to date, the result is: The greater the move toward deinstitutionalization (even with the increasing costs per patient in institutions resulting from the declining patient populations, improved staff/patient ratios, and escalating fixed costs), the greater the savings to *both* Federal and state governments. We also calculate the fiscal effects of a Medicaid cap. The only effect of a Medicaid cap is that, instead of large state savings through Medicaid funding of community services (as is the case for deinstitutionalization in a no-cap situation), there is a minimization of state losses (in the cap sitaution). In either case, cap or no-cap, the Federal government can expect to save considerably under a deinstitutionalization strategy.

One of the most dramatic results of this analysis occurs where there has been a court order or consent decree requiring a state to phase down its institutions and where the state has been reluctant or unable to follow the required time schedule. In these states (most notably Nebraska, but also Pennsylvania and Minnesota), the stratagem of *not* following the required time table has resulted in large increases in net state costs of care, compared to what it would have cost the state if the consent decree had been implemented on schedule. (In Nebraska, we estimate a loss to the state of nearly $80 million over the past four years.)

To summarize: The investment of public money at each level of government contributing to the cost of care in the MR/DD system is less under a deinstitutionalization initiative (where full cost accounting is practiced for all income maintenance, social, medical, and educational services, where the level of services meets current Federal regulations governing institutional and community programs, and where the quality of services matches that of exemplary services selected from different states) than it is under a plan that continues institutionalization in its present form.

Senator WEICKER. Thank you very much, Mr. Copeland, and I thank each member of the panel. I am going to reserve questions at this juncture, because we do have five more panelists, and the hearing has got to conclude by 12:30. So I would like to proceed to the next panel.

Now, if there are any further comments that anyone has to make, they will certainly be accepted for the record. All the statements will be taken in their entirety in the record. Are there any statements as the panel leaves? I do not like to foreclose anybody. Is there anything that anybody really wants to get off their chest here, that they can do in about a minute's time.

One minute, Elliot. Go right ahead.

Mr. DOBER. In regard to the opening remarks of the administration, and in regard to block grants, when they made the comment that the States would take over the programs, and you made the comment whether they would or they wouldn't, it is my judgment, and only my judgment, that without the Federal mandate for DD and P and A, that the States would not take over this responsibility. They would not protect the rights without having a Federal mandate. They would not categorically fund the DD population, because they would get lost in other funds.

And Senator, you have been in State government, I have been in State government, and we both know how things get lost in government. So without the law, without the mandate from the Federal Government, it would get lost, and handicapped and disabled people will be pushed back farther. We have come a long way because of this committee, and I would hate to lose any ground.

Thank you.

Senator WEICKER. Thank you very much, Elliot. I very much appreciate yours and the comments of the other panelists.

[The following statements were received for the record:]

STATE OF CONNECTICUT
OFFICE OF PROTECTION AND ADVOCACY FOR HANDICAPPED
AND DEVELOPMENTALLY DISABLED PERSONS

Eliot J. Dober
Executive Director

I. I am Eliot J. Dober, the Executive Director of the Connecticut Office of Protection and Advocacy for Handicapped and Developmentally Disabled Persons.

I would first like to thank Senator Weicker and the other members of this subcommittee for the opportunity to outline to you the continuing need for a Protection and Advocacy system nationwide.

I offer my comments today based on my experience as Executive Director of the Connecticut P & A Office, one of 54 such agencies which have been in operation since the passage of Public Law 95-602 in 1977. Within this extensive network of P & A agencies there have developed a wide variety of approaches and emphases in serving as an advocate for people with disabilities. I believe, however, that whatever variations exist in terms of delivery of advocacy services, our experience in Connecticut is representative of the continued need experienced by the disabled and handicapped community across the country for a P & A system.

This testimony is organized around two central themes: a general statement describing the ongoing necessity for the P & A system, and a review of our experience in Connecticut as an illustration of the services we provide and the needs that remain.

II. General Consideration

When Congress created the P & A system, it recognized, I believe, that a number of factors conspire to place handicapped citizens in a situation in which their right to appropriate services and equal opportunity frequently cannot be realized without the

assistance of a vigorous advocacy network. It is my judgment that while the Protection and Advocacy system has made significant contributions toward alleviating some of the problems encountered by handicapped persons, the special and unique needs of handicapped persons require the continued existence of an effective advocacy system. In addition, the social service delivery system has not yet reached a point where it operates without generating frequent confusion and sometimes outright discrimination in the provision of services to the population whose needs they are mandated to meet.

Many developmentally disabled persons are unable to serve as their own advocates. The nature of their handicapping conditions: mental retardation, neurological disorders such as cerebral palsy and multiple sclerosis, sensory impairments such as deafness and blindness are frequently incapacitating to the extent that disabled persons are not able to adequately protect their own rights. Our experience in Connecticut, as described in the subsequent section, amply confirms Congressional findings that many disabled persons require the assistance of advocacy services.

Developmental disabilities are lifelong in nature, i.e., mental retardation, cerebral palsy, etc., are not cured. Therefore, while progress has been made by the P & A system in obtaining greater adherence to the rights of handicapped persons, the underlying frequent inability to champion one's own cause will inevitably continue to be a fact of life for many disabled persons.

Developmentally disabled persons have been segregated from society, denied equal rights and services which would permit them to achieve their maximum potential. For example, the squalid conditions faced by many institutionalized developmentally disabled persons have

been and remain well documented. Daily discrimination and treatment as second class citizens are and remain a fact of life for many developmentally disabled citizens.

In recognition of these problems Congress, and in particular, this committee, have enacted a variety of federally funded programs aimed at assisting handicapped persons. Public Law 94-142, providing equal educational opportunities for handicapped children; the Vocational Rehabilitation Act which authorizes training for disabled persons; Section 504 of the 1973 Rehabilitation Act which mandates architectural and program accessibility and prohibits employment discrimination; and Title XIX of the Social Security Act are examples of the courageous steps this committee has taken to provide federal assistance to handicapped citizens. The Protection and Advocacy network has played an instrumental role in assuring that all of this vital federal assistance is made fully available to disabled persons. In Connecticut, for instance, as described below, most of our advocacy efforts focus on assisting disabled persons and their parents in obtaining the very rights and benefits placed into being by this committee.

III. Connecticut P & A Office

As I stated in my opening remarks, although I can only speak about the activities of Connecticut's P & A, I feel our almost four years of experience are representative of the activities of the fifty-three other P & A offices.

We assist the parents of disabled people as well as disabled individuals to ensure that a full range of services are in place to meet the needs of handicapped persons. Approximately 40% of our calls are from the parents of disabled persons. About 50% of our calls originate from representatives of social service agencies

who, in attempting to obtain needed services for their clients, turn to the special advocacy expertise that P & A can provide.

Since its first year of operation in October 1977, Connecticut P & A's major areas of activity have evolved into five functional components:

1. Individual Case Advocacy: this is provided on a statewide basis by three advocates (details of the Individual Case Advocacy Component are provided below);

2. Citizen Advocacy: this is provided on a statewide basis by one Citizen Advocacy Coordinator. Citizen advocacy can also be rererred to as community organization or community mobilization. The "community" in this case includes people with disabilities and parents/guardians of people with disabilities. The goal of the Citizen Advocacy component is to train consumers and their allies in effective advocacy techniques, including an awareness of their rights, assertiveness training, and lobbying skills. Our Citizen Advocacy Coordinator provides ongoing training programs for disabled persons regarding Section 504 of the 1973 Rehabilitation Act, and a training program for the parents of disabled children regarding Public Law 94-142, the Equal Education for All Handicapped Children Act. Our Citizen Advocacy program is in the continuing process of building a strong coalition of parents to support the development of expanded respite care programs in Connecticut, to assist these parents in caring for their severely disabled children in the home.

3. Public Information and Education: this is provided on a statewide basis by one Publicist. Community outreach is one of the most important components of our public information program. Our

Publicist organizes and participates in numerous conferences, seminars, and speaking engagements designed to provide both consumers and the general public with information regarding the Office, its services, and the rights of people with disabilities. These awareness programs are conducted with private and public agencies, civic organizations, consumer groups, high schools, colleges, local and state administrators and parent groups.

In the past year, our outreach programs generated the highest visibility our Office has experienced in its three years of operation. The programs have been conducted in both rural and urban areas across the state, with a goal of creating an informed statewide network of advocates, consumers and parents.

There is still a great need to provide expanded outreach to institutionalized persons and disabled people of racial minorities. At the present time, the Office is faced with both the realization of this need and the practical reality of only one staff person with the primary responsibility of providing public information programs. We were also cognizant of the increased caseload our public outreach has generated in the last year, a caseload that is still divided among only three advocates.

In an attempt to deal with the problem, the Office will recruit volunteers in the next year to assist the Publicist in community outreach to groups not previously affected by our current outreach efforts.

4. Legislative Advocacy: this is performed by me as the Executive Director with the assistance of one law student intern who is employed on a part-time basis. For the third consecutive year, the Office coordinated the activities of the Legislative

Coalition for Handicapped People. The Coalition was co-chaired by Hartford Easter Seal Rehabilitation Center Executive Director, David V. Daughtery, and me. The forty-eight member group (which consists of over one-hundred fifty individual members), includes service providers, advocacy organizations, individuals with disabilities and parents. The Coalition developed a seven bill priority package which was introduced to the 1981 General Assembly, and functions as a grassroots coalition to encourage the passage of key state legislation for disabled persons. The Coalition, with the assistance of our Office, has generated a great deal of awareness on the part of state legislators of the needs of disabled persons, as well as obtained passage of state legislation which will ensure disabled persons the opportunity for greater independence, self-reliance, and mechanisms to provide their legal and human rights.

5. Legal Advocacy: this is provided by one attorney employed full-time and one attorney employed on a part-time basis. The attorneys provide a variety of services: advice to the Office advocates; direct representation of disabled persons and their parents in administrative proceedings such as special education appeals as well as in judicial proceedings; and technical assistance in matters pertaining to legislation.

One frequent misconception regarding P & A needs to be clarified: the fact that only 2 percent of 68,000 cases handled by P & A agencies nationally in our first three years required court intervention is an indication that society, programs and individuals are able to work cooperatively to meet the needs of individuals who are developmentally disabled. The fact that very few of the cases required court opinion speaks well of society's desire to provide adequate programming and services for people who are

developmentally disabled. Also, the fact that only 2 percent of the cases required litigation speaks well of the skill of the individuals who staff the P & A agencies in their ability to obtain appropriate programming and appropriate services without the need for court action to secure the desirable outcome. The statistics would indicate that the fear that constant court intervention would be necessary and used by the P & A system was immensely overstated.

Individual Case Advocacy is the heart of the P & A system. We were established to fight for the rights of those individuals who have no voice of their own. The clients and their families who seek our assistance do so because they have been denied needed services: Our Office is usually their last resort. Our mission is quite simple: to obtain for disabled people needed services to which they are entitled, and which they frequently cannot obtain from the appropriate service provider. Without us, these people would be lost in the current fragmented social service bureaucracy of the state and federal government.

From October 1, 1977 to October 31, 1980, Connecticut's P & A:

1. Provided individual case advocacy to 2,149 disabled individuals in Connecticut.

2. Provided information and referral (general information assistance) to 2,935 callers.

3. Subcontracted through Title XX with three private advocacy groups to supplement our individual case advocacy. These groups provided individual advocacy to over 300 disabled individuals and information and referral assistance to over 4,000 callers.

4. Subcontracted through Title XX with Connecticut Legal Services and the Legal Aid Society of Hartford County to provide

legal representation to residents of state institutions and local communities, resulting in 150 additional individuals served.

From October 1, 1977 to October 31, 1980, Connecticut's P & A, in its individual case advocacy function:

1. Handled 371 cases regarding special education under Public Law 94-142. These cases range from representing the parents of disabled children at special education meetings to representing parents at special education mediations with school boards and formal hearings with state hearing officers regarding parents' special education complaints. The implementation of Public Law 94-142 is by far the activity that comprises the majority of our individual cases.

2. Handled 72 complaints regarding institutional care, many of which involved parents, advocates, and institutional staff allegations of physical abuse, excessive use of physical and chemical restraints, and alleged deprivation of residents' legal rights in Connecticut's mental health and mental retardation facilities.

3. Handled 293 cases involving problems with state and federal financial entitlement programs. These cases involve disabled persons who have been denied SSI or SSDI and need representation for their appeal to the Social Security Administation. These cases also reflect various difficulties disabled persons experience in obtaining Title XIX benefits and services. Our advocates provide formal representation, technical assistance, and support for disabled persons and their parents attempting to work their way through the current maze of financial entitlement programs.

4. Handled 262 cases involving the employment concerns of disabled persons. These cases range from the problems of disabled

persons who can't obtain employment due to a lack of appropriate education and training, to the problems encountered by disabled people who still face widespread discrimination in the job market. Our advocates work with both private and public vocational rehabilitation agencies to ensure that our clients are receiving the individualized rehabilitation programs appropriate to their needs. Our advocates also work with employers in the private and public sector to assist in the implementation of Section 504 of the 1973 Rehabilitation Act.

5. Handled 148 cases involving disabled persons' transportation problems. These cases range from the complaints of disabled persons who have been unable to obtain access to Connecticut's newly accessible buses, to the problems disabled people encounter with local transportation systems that are ill-equipped and unable to meet their daily transportation needs. A lack of accessible transportation impacts directly on disabled persons' ability to obtain or maintain employment and their ability to lead productive, independent lives.

6. Handled 217 cases involving the housing problems faced by disabled persons. These cases involve assisting disabled individuals in locating accessible, affordable housing that meets their individual needs, and helping disabled persons with the process of applying for Section 8. Many disabled persons still face severe discrimination from landlords who do not wish to rent to people with disabilities.

These six areas of concern to disabled persons are just a few of the many areas in which disabled persons and their families rely on our advocacy services. Other areas include assistance in problems with architectural barriers, medical equipment, protective services, human rights, commitment hearings, insurance, and recreation.

Although in Connecticut our P & A also operates under a state statute which mandates our provision of advocacy to all handicapped as well as developmentally disabled Connecticut citizens, for the purposes of this committee I will concentrate on the numbers of developmentally disabled persons we have served.

From October 1, 1977 to October 31, 1980, Connecticut's P & A served:

1. 231 persons with mental retardation
2. 165 persons with cerebral palsy
3. 150 persons with epilepsy
4. 32 persons with autism
5. 39 persons with muscular dystrophy
6. 47 persons with birth defects

In addition to the above, our P & A served 140 blind or visually impaired persons and 87 deaf or hearing impaired persons, as well as people with spinal cord injuries, psychiatric disabilities, and neurological disorders. It is important to note that we have also served over several hundred additional developmentally disabled persons who are multiply handicapped with severe disabilities.

As I stated before, our Office is frequently a last resort for parents and disabled individuals who have not been able to obtain the services they need and to which they are entitled by law. The following represents a few examples of cases in which our P & A has aided developmentally disabled individuals in acheiving or maintaining their rights:

* Demonstrated that a nursing home was an inappropriate placement for a mentally retarded person and secured appropriate placement with an individualized habilitation program in the community.

* Obtained the re-employment of a person with epilepsy who was discharged from employment.

* Secured an accessible apartment in a Section 8 funded apartment complex for a man with severe cerebral palsy after he had been discriminated against for being "too severely disabled to live independently." Arranged for a personal care attendant to assist the individual with his personal needs.

* Assisted a mentally retarded person who had been institutionalized for 22 of his 29 years in his transition from the institution to a community group home. This involved successful placement in a sheltered workshop plus adjustment counseling for the individual and his family.

* Secured a twelve month education program for a group of developmentally disabled children who otherwise would suffer from regression during a three month vacation.

* Secured the provision of occupational therapy and physical therapy within the school program for individuals who are developmentally disabled.

The Protection and Advocacy System provides the mechanism which allows representation of individuals as they are confused, confronted, and sometimes denied access to services and developmental programs during crucial periods of their lives.

Our history more than adequately demonstrates the high quality advocacy our P & A has provided in its fulfillment of the federal mandate initiated by this committee.

STATEMENT OF TESTIMONY

BEFORE THE

SENATE SUBCOMMITTEE ON THE HANDICAPPED

RE: DEVELOPMENTAL DISABILITIES PROGRAM

BEVERLY E. JACKSON
65 CONSTANCE LEIGH DRIVE
NEWINGTON, CONNECTICUT

APRIL 30, 1981

Senator Weicker, Members of the Committee, Ladies and Gentlemen:

My name is Bev Jackson. I am a resident of Newington, Connecticut. I am here today representing the Connecticut DD Council for which I serve as a member of the Evaluation Committee.

I am also here as a consumer. I have cerebral palsy and I am developmentally disabled. As you can see and hear, I have some communication problems and I am mobility impaired. Also, I am not gainfully employed. Unlike persons who become disabled as a result of an accident or war, and who must learn to adapt to their environment, I was born with my disability. At some point during the birth process, while still in my mother's womb, the oxygen supply to my body was cut off, resulting in my degree of brain damage. I feel very fortunate that I am not more disabled than I am. In fact, many DD persons are much more severely disabled than I. I can take care of myself - others need much more personal attendant care. I can speak - others have no speech. I received a normal education - others need special education. I can walk - others are dependent upon a wheelchair. I can make my own decisions - others need daily guidance. I can live independently - others need supervised living arrangements. Finally, I believe I could work if our rehabilitation system served multiply handicapped persons - others will never be able to work. Yes, I can do all these things, but because I was born with a disability, I did not have the opportunity to gain the experience and skill acquired during normal childhood development. I did not have the opportunity to experience life without assistance. I did not have the opportunity to acquire social development skills. I did not have the opportunity to experiment with independence. I was born developmentally disabled. While persons who acquire a disability later in life have these experiences upon which to base their <u>re</u>habilitation, my needs were more difficult to meet. I needed to be <u>habilitated</u>.

The degree of disability associated with my cerebral palsy causes me to be developmentally disabled. The DD population includes the most severely and multiply handicapped persons within all categorical disabilities that occur during the developmental years. The DD population has historically been unserved, underserved or "warehoused" by all public and private providers due to the difficulty in serving this population. Unlike the state Departments of Mental Retardation or Mental Health, or Associations for Retarded Citizens, United Cerebral Palsy Associations, Societies for Autistic Children or Epilepsy Foundations, there is no state Department of DD or private DD Associations. DD program "seed" grants and the Council's influencing powers have been used to leverage others' programs and resources to benefit the DD.

Since 1971, Connecticut has expended $3.3 million of DD funding. Seventy-nine percent ($2.6 million) has been used for service grants to 57 private and public agencies. Twelve of those grants are programs in their first, second or third year of "seed" grant funding. Forty (40) of these grants went to private agencies, 16 to state agencies and one to a municipality. These funds leveraged services to the DD in public and private programs for the mentally retarded, cerebral palsy associations, universities, hospitals, Easter Seal agencies, autism societies, epilepsy associations, other state agencies and numerous non-categorical disability providers. Three thousand nine hundred and eight (3908) DD persons were served by these grants. We have used 21% of our grant funds for case management services, 26% for alternative community living arrangement services, 24% for child development services, 22% for nonvocational social development services, 3% for research and 4% for employment services. None of our grants were for institutional services. Equally as important as the services provided with DD dollars is the fact that each of our grantees also provided one or more secondary services to the DD with their own resources.

Removing the DD program influence will affect decisions about policy toward the DD population. Without the influencing ability of the DD program, agency eligibility criteria will revert to serving only the "cream of the crop." As massive federal budget cuts pass through state government to local interest groups, it will be quite easy for the DD interests to get trampled underfoot in the rush of special interests to preserve some level of their programs. The categorical DD program provides a platform for DD persons to be seen and heard and sets the standards of services necessary for the DD population.

The DD program addresses the needs of the most severely and multiply handicapped. These needs frequently are not met by a single generic or specialized agency. Instead, services are needed from a variety of agencies in an integrated service network. The DD program has provided the states with a model of the essential components of an integrated service delivery system and it has challenged public and private agencies to provide the necessary service delivery networks. The DD program cross-cuts not only human service programs, but also health, education, transportation and other programs to bring all these resources to bear on the DD population. For example, our Council has been effective in assuring that the needs of the DD were addressed in our State Health Plan and outdoor recreation planning. We encouraged consumers to become involved in the policymaking and planning in vocational rehabilitation. We influenced the development of a new rate-setting system for operators of private alternative living programs and the Council's efforts made available $1.5 million in Department of Housing and Urban Development, Section 202 construction funds for agencies serving the DD and physically handicapped. We are exploring ways to augment an interagency collaborative project in New Haven, exploring adoption and foster care services being provided to the DD and trying to develop a licensing program for residential

programs serving the non-mentally retarded DD. We funded a Corporation for Independent Living to serve all disabilities and expanded homemaker/health aide services to the DD in the Willimantic area.

Blocking the DD program negates these past cross-cutting achievements and stifles efforts to create an integrated service delivery system.

States have not and cannot protect the DD without federal leadership. The severely handicapped are always the last served and states have historically "warehoused" the DD in expensive institutions. The DD population has been subject to abuse and neglect without a focus within state government to plan for, monitor and evaluate services and to protect the rights of the DD. The Connecticut DD Council has even used its influencing power to coordinate several state agencies in the investigation of unethical practices of a private agency.

As a consumer member of the Connecticut DD Council, I am proud of my role in seeing that DD needs are being addressed and knowing that our Council has recognized, acted upon and is supportive of the "consumer movement." My role is one of satisfaction and growth.

I am a participant in every aspect of the planning and the delivery of services designed to benefit the DD or to alleviate the problems of the DD. Not only am I consulted, surveyed, studied and evaluated, I am an active participant in the planning process, wielding decision-making power equal to that of the professionals and planners on the Council.

As a consumer, I am the best advocate for myself and for other DD persons and their families. As an advocate, I speak for them, act in their behalf and in their best interests. Services that we create to meet the needs of the DD also meet the needs of their families.

I do not know everything the professional has learned after years of study. It is equally true that the professional does not know everything I

have learned after years of living with a disability, often being put down, turned down and cooled out by insensitive professionals who do not know what to do, and who will not or cannot admit it, and by the bureaucratized service system.

I have taken the initiative to pound on the door, when necessary, in order to participate where I rightly belong. I have found that I have had the greatest impact on the system when I approach professionals as if they were potential friends and allies. Often it is simple ignorance on the part of professionals regarding my level of participation and involvement. In this case, I have taken the initiative to educate the professionals.

The DD Council provides the organization to continue communication among consumers, between consumers and planners, and between consumers and service providers. The Council provides the forum for a number of people, usually isolated from each other and struggling with their problems alone, who have common needs and problems. We can join together and direct all of our energies toward changing laws, attitudes, systems and individuals who are putting us down and dealing us out. As an example, through the Council, and in collaboration with our Protection and Advocacy Office, we have organized more than 30 public and private agencies into an effective Legislative Coalition that impacts the Connecticut General Assembly, not only on behalf of the DD but on the handicapped in general.

It is becoming even more apparent that DD persons will need the DD Council to gain services we all commonly need, but that we would be hard pressed to get on our own. Consumers on the Council bring strong leadership together, provide situations in which we discover areas of common interest and plan unified action that benefits all concerned. Because consumers needs emerge on the Council in ways that do not threaten the special needs of individual groups, our impact has been substantial and invariably beneficial.

One of the best ways for consumers to be sure that services and programs set up to serve the DD are actually doing the job is through constant monitoring and regular evaluation of these systems and programs. Consumers, who know what ought to be provided by particular programs are in a good position to make evaluative judgments. As a consumer, I may not be in a position to correct problems discovered through monitoring and evaluation, but I can see to it that an accurate statement of the difficulty is presented to people who can. And if the problem is not solved satisfactorily, I can proceed up the line of authority, presenting the problem accurately and firmly at each level, until something is done about it. If all else fails, I can take it back to the Council.

Monitoring and evaluation require much of my time, energy and commitment. We conduct an annual site visit evaluation of all of our grantees and our Protection and Advocacy Office. We evaluate these programs from the perspective of the consumer, as the Council uses individual development as a measure of our grantees' success. This past year, we examined the number of handicapped and minority people hired by past and present grantees and met, with great difficulty, federal requirements for a comprehensive evaluation system. We are currently funding a field-test of implementing that system and this data will be used to conduct an evaluability assessment of selected DD programs. Finally, in the interest of providing quality services to the DD, the Council funded a project to help community-based DD service providers acquire national accreditation and certification.

I am but one of eleven disabled people on the Connecticut DD Council. There are another eleven parents of disabled children and adults. We are all consumers. I do not automatically know everything every other consumer knows. However, I am confident that my own viewpoint and my own experiences are valuable. I express those viewpoints and share those experiences, but I understand they

may not be universal. I make every effort to know their needs and wants. I see it as my duty to see that they are contacted, talked with, involved, polled and listened to and that their needs are met by the services the Council helps provide. I insist that every element of any program the Council designs has consumer input and involvement and that every element is accountable to the DD people served.

The DD Council provides an excellent forum for consumer initiative. Here, consumers are key members of groups responsible for planning, developing and improving the quality of services for people with DD. The Council provides support for consumers at the local level in securing their rightful places in service delivery activities. Finally, the Council is a source of information to consumers and a resource for incorporating local consumer data and perspective at the state level.

I respectfully ask this Committee to not consolidate the DD program into any block grant to states and to not reduce our appropriation below current appropriated levels. I ask you to extend the DD Act as a separate program. The Connecticut DD Council has launched efforts to target severely and multiply disabled persons residing in long-term care facilities, DD persons with severe mental health problems, severely physically disabled/medically involved infants and children severely brain damaged as the result of trauma. We are also exploring the needs of the aged and aging DD. This is the most ambitious program in the history of the Connecticut DD program. We hope you will continue to provide the leadership.

Thank you very much for this opportunity to present the Council's and my own personal views.

STATEMENT OF

ETHAN B. ELLIS,

DEPUTY DIRECTOR,

OFFICE OF ADVOCACY FOR THE DEVELOPMENTALLY DISABLED,

DEPARTMENT OF THE PUBLIC ADVOCATE

STATE OF NEW JERSEY

Mr. Chairman and Members of the Senate
Subcommittee on the Handicapped:

I ask you to renew the legislation establishing the federally funded developmental disabilities programs. I specifically ask you to reaffirm the Congress' commitment to encourage the protection of rights of persons with developmental disabilities and to the mechanism it has designed for that purpose, the state Protection and Advocacy Systems.

In less troubled times, this would be an easy request to make and to support with data demonstrating the merit of that request. This is an easy program to support. With modest funding, it has done all that the Congress has asked it to do for Americans with developmental disabilities. It has accomplished much which those of us with disabilities thought was beyond reach when the Protection and Advocacy Systems first began half a decade ago. Ordinarily, I would come to you with pride in those accomplishments, outline them to you with the enthusiasm born in the knowledge of a job well done, and ask you for the resources to do even more.

But these are troubled times. America faces an economic crisis and the solutions proposed by some would reduce services to all persons with disabilities. Historically, these services have been least available to those with developmental disabilities. In the best of times, their need for advocates has been great. It will increase as services shrink.

The Protection and Advocacy Systems were born in response to the nation's shock and revulsion at the revelations of abuse, neglect, and public abandonment of persons with mental retardation and other developmentally disabled people in institutions run by state agencies throughout the country.

Have the factors which led to such conditions in state after state changed that much in six years? Will they not be exacerbated in light of reduced federal support and the cramped budgets of state agencies? Today, in view of the prospect for reduced services, the need for Protection and Advocacy Systems is more compelling than it was six years ago when these systems were created.

In the mid-1970s Congress passed a series of statutes which acknowledged that those of us who have disabilities are fully human, too. You granted us rights which affirmed that humanity and you reorganized and augmented the service systems which support us so that we might obtain that humanity and achieve full citizenship. These service systems have begun to provide us with appropriate educational opportunity, employment training and work experience, and other assistance which prepare us to live more independent of government aid. Discrimination against disabled people was outlawed.

You recognized that we had been denied those rights, that humanity, that full citizenship, by many of the very state and local governments and private agencies which you had funded to provide services to others. To remedy that, you built safeguards into those statutes for our protection -- fair hearings, due process procedures, and access to the courts -- to provide us with recourse if those governmental and private agencies continued to ignore our rights and deny us service.

In the case of persons with developmental disabilities, who are particularly dependent on the services of these agencies and uniquely unable to protect themselves from abuse, you established a state-based program of protection and advocacy to act on their behalf. You also established state planning councils and incentives for the states to improve the care to

developmentally disabled individuals by encouraging better planning and coordination.

Now, in the name of economic recovery, you are being presented with a program which would repeal those rights, reduce those services, and make us dependent for the reduced services which remain on the very state and local agencies which denied them to us in the past. Will their capacity for compassion toward their disabled citizens increase when they contemplate the reduced federal support for those citizens in the light of their own shrinking budgets?

People with developmental disabilities cannot long maintain their humanity in the face of a hostile society led by a hostile Congress. People with developmental disabilities cannot achieve more independent and productive lives without uniform federal guarantees of protection of their rights and access to the services they need. It is in this spirit that I ask you to consider the Protection and Advocacy Systems for persons with developmental disabilities.

Let us look briefly at how these Protection and Advocacy Systems have performed. Because they were born out of Congressinal concern over the abuse and neglect of persons with mental retardation and other developmental disabilities residing in state institutions, they were charged with the responsibility of seeing that such persons received adequate care and treatment in the least restrictive setting appropriate to their needs. They were thus recognized as implementers of Congress' stated policy of favoring deinstitutionalization where that best met the needs of individuals with developmental disabilities. They were armed with the authority to seek legal remedies on behalf of their clients because of the enormous power of the bureaucracies which often cause them to be abused, neglected, or denied

services. They were charged with the responsibility of using that authority with restraint and only as a last resort.

During the last two fiscal years for which statistics are available, 1979 and 1980, the Protection and Advocacy Systems provided direct services to 68,700 persons. In only 1.8 percent of those cases was court intervention required. That all other complaints were resolved through negotiation or some other informal means of intervention is a tribute both to that restraint and to the potency of that authority, as well as the knowledge of the service delivery system developed by Protection and Advocacy Systems and their ability to cut through red tape.

Each Protection and Advocacy System was charged with making its services available on a statewide basis thus assuring advocacy for persons with developmental disabilities who lived independently or with assistance in communities as well as those who lived in institutions. This has involved them in issues of adequate community programming and education. It has also stretched their slender resources to capacity. To meet this challenge, they trained persons with developmental disabilities and their relatives and friends in their legal rights and entitlements and in the skills and strategies of self and lay advocacy and knit them together in advocacy networks which they supported with the materials which they developed, with staff and pro bono legal advice, and with legal intervention where necessary.

From their inception, Protection and Advocacy Systems were designed to be responsive to the social and political contexts of persons with developmental disabilities and the services which they received in their particular states. Each governor was empowered to designate the agency, public or private, which served as that state's Protection and Advocacy System so long

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as that agency was independent of other service providing agencies. The fact that so few Protection and Advocacy Systems have been redesignated in the face of the often delicate task of representing their client's interests against the authority of the state is a tribute to the support they have developed among their developmentally disabled constituents as well as to the sensitivity of their Congresional designers who developed a delicate but lasting balance between federal authority and state flexibility in implementation.

I urge you to maintain that balance. I urge you to continue the Developmental Disabilities Bill of Rights Act and the Protection and Advocacy Systems which undergird it.

As I do, I am mindful of the intense public struggle over the size of the federal budget and the huge sums that are being spent to convince you that Americans no longer support such programs as these. As you count the mail and telegrams and phone calls which this campaign generates, I ask you to consider how many of them specifically oppose programs which sustain the rights and services which America's disabled citizens need in order to live more productive lives. Then I ask you to ponder where we who are disabled might raise similar funds to make our voices audible in that din. Having done that, then make your judgment as to whether Americans truly oppose such programs; then make your decision as to whether they should continue.

Senator WEICKER. The next panel, relative to meeting the needs of persons with developmental disabilities, priority and other specialized services, will have on it Dr. Norris Haring, of Seattle, Wash., relative to child development services; John DuRand of Minnesota, Vocational Training and Employment—John is the president of Minnesota Diversified Industries; Jerry Provencal of Michigan, director of the McComb Oakland Regional Center, Alternative Community Living Arrangement Services; and Julie Ewing, of Graham, N.C., on Case Management Services.

I do not know who is first up here, but whichever way you have designed it, please proceed.

Dr. Haring.

STATEMENT OF DR. NORRIS G. HARING, UNIVERSITY OF WASHINGTON; JOHN DURAND, PRESIDENT, MINNESOTA DIVERSIFIED INDUSTRIES; JERRY PROVENCAL, DIRECTOR, McCOMB OAKLAND REGIONAL CENTER, AND MS. JULIE EWING, CASE MANAGEMENT SERVICES, GRAHAM, N.C., A PANEL

Dr. HARING. Thank you very much, Senator.

I am very impressed with your endurance Senator Weicker, and I will not take advantage of it any further. I have been working on how to cut back several pages of testimony and have had the advantage of several other panels.

I think we are all aware of the urgent nature of our economy and the responsibility that you have to look at it carefully and to make some careful decisions.

The data that I have brought and include in my testimony has been prepared largely for this hearing. It is designed essentially to show that we can spend money now in order to save money in the long haul; this, basically, is what we can show as we build and support programs for handicapped individuals very early in their lives. I am talking about early education programs for the handicapped.

I intend to show that these programs have been exceedingly cost-effective and that they are in fact a good investment for the future.

We have evidence, which I have collected and which I will show, to demonstrate that we can intervene effectively with very young handicapped individuals and in that process, return a number of these individuals to regular educational programs by school age. The most effective early programs start with the child at birth, and the programs become slightly less effective as they start each year after the birth of the child.

So basically, that is the role that I have agreed to play, and my own testimony is to demonstrate that money spent very early on the handicapped provides us with excellent investment.

We have made, in recent years, some tremendous advancements in early intervention. We have found that infants can make discriminations just a few weeks after birth. We have utilized this information to develop a basic and effective strategy for intervening with handicapped individuals. Many handicapped individuals can be identified at birth. More than 85 percent of our severely handicapped individuals can be identified within a few weeks after birth, during their neonatal period.

Our programs, many of which have been federally funded, have started in many cases with handicapped individuals at infancy, and they have started the counseling, conferencing, and education of the parents of these individuals very early.

We have discovered that through systematic instruction we can reinforce appropriate behaviors and help the very young handicapped progress through early developmental sequences of gross and fine motor coordination, communication, social development, and self-help and cognitive skills. These intervention efforts can be measured and shown; in our recent study with Down's syndrome infants, where we have been able to follow up the Down's infants who had had intervention 8 years after the early and first intervention period. Many of the gains that were shown during the first weeks and months of our intervention have been maintained throughout several years of these individuals' lives and have provided tremendously accelerated increases in academic achievement as they have entered school. In fact, one of the greatest problems in following up these Down's infants has been that as we return these children from our intervention program to the Seattle schools, they were dispersed, some of them in regular classrooms and some of them in very natural settings throughout the schools, which made it difficult for us to continue our research with them.

I intend also to provide a brief description of this program. Our program and many of the other programs for very early education for the handicapped were funded by the Office of Special Education and with cooperative funding by the Developmental Disabilities Act.

The program that I am referring to now is the handicapped children's early education program. These projects have provided seed money for early intervention. The projects that were funded for 1980 and 1981, provided services for over 2,849 children and their families. These projects trained many other service providers, developed curriculum and assessment instruments, and disseminated demonstration information.

Outreach projects that have come out of this program have trained over 25,000 professionals. They have established 640 replication sites, serving 18,400 children. These projects have been subject to careful scrutiny and tracking. Each project was required to develop an evaluation component, and, in addition, HCEEP issued subcontracts to external evaluation specialists, such as Abt Associates and Battelle Institute, to make sure that these projects were effective and cost efficient.

I am going to concentrate now on a series of overheads. I want to demonstrate with these overheads that these projects can be continued once they are started with seed money.

On the vertical axis is a percent of the projects that were continued after the funds from the Federal Government were discontinued.

In the study, which was done in 1980, using the original 21 projects started in 1969 Bill Swan found that 86 percent of the projects continued some of the components of the model after the funding had been discontinued. A study done by Daniels and Jackson, using 17 projects, showed that 100 percent of the projects continued at least some of the components after the funding discon-

tinued. The most recent study by Cox and Taylor-Herschel was done in 1981. They had 53 projects in their study and found that 63 percent of the projects were continued in the community after the funds had been discontinued.

Continuing on, in the Swan study, he found that 52 percent of the projects continued the full services and even expanded on those services. Daniels and Jackson found that 59 percent continued full service or expanded on those services. And Cox, Taylor-Herschel found that 24.5 percent of the services were continued in full, and/or expanded in those projects.

The point that I wish to make here—and I think these data make that point well—is that these projects funded with a minimal investment of Federal seed money, were able to continue services after the Federal funds were discontinued.

Senator WEICKER. I want you to continue, Doctor, but I also want to apprise you that we do have a little bit of a time constraint here for the other panelists.

Dr. HARING. This slide is designed to show the sources of funds after the basic support is discontinued. It also shows the percentage of projects receiving local funds as reported in the Swan, Daniel and Jackson, and the Cox, Taylor-Herschel studies. As you see here, the percentage of local funds in the Swan study was 86 percent. In the next study, local funds were provided in 41 percent of the projects, and in the third study, in 50 percent of the projects. The average of local funds which were used to continue these projects in the local community by the local education agencies was 59 percent.

The first study found that 66 percent were continued basically by State funds, the State education associations. In the next study, we have the funds continued by the State in 88 percent of the cases; and in the third, by 41 percent of the cases.

In the last overhead, I am talking about costs. Early education for the handicapped has a tremendous effect on whether or not the handicapped individual will be able to return to a regular education program.

In the case where we begin early education at birth, by school age, out of every 1,000 kids, only 389 need to continue on in special education. The rest are able to integrate into regular education programs. When early education starts at 2 years of age, by school age, only 442 handicapped individuals have to continue their education in special classes. The rest of the children can remain in regular education.

Now, on an average, special education costs about $4,400 per year per child. Regular education costs about $1,400 per year per child, something a little over a fourth of what special education costs.

Now, if we do not provide early education and bring handicapped children into school at school age, which is on an average 6 years of age, we only have, out of 1,000 kids, a little over 350 that return to regular education. Out of that 1,000, 650 remain in special education, where the cost for education for their lives is considerably more.

I would like to summarize by saying that we have, in this program and in other programs that I have been involved in at the

University of Washington, been very concerned about block funding. Our major concern is whether or not the funds will actually get to the population that we have targeted for intervention. We have had experience in the past with title III, and found that even had to pass an amendment to that legislation in order to get a set-aside of 15 percent for the handicapped. The data I have shows that before we passed that amendment, less than 3 percent of the money from title III actually went to the handicapped. Although a block of funds has some advantages, the major disadvantages come from our inability to be able to designate as it comes to the State whether it will in fact go to targeted populations.

Another problem that we have with Public Law 94-142 is the problem that it does not provide for the education of very young handicapped kids, because its authorization starts at three.

Some of us have been doing research in this area of intervention, and believe that most of the good news for change is over by 3 years of age as far as the handicapped are concerned.

As we look at that legislation, I would like to speak strongly for amending and revising it in such a way that it authorizes educational programs down to at least 1 year of age, because our data here that I presented and which is in the testimony will demonstrate that that is the most effective time to start. By then, we know that we have, or pretty much know that we have a handicapped individual involved, and second, we know that that is the optimum time to begin our intervention.

One of the things that has been concerning me about the testimony—and I will end on this—is the fact that we have and can save money by deinstitutionalization, but there is no way that we save money there unless we consider ways in which we can strengthen the community services for these individuals who are deinstitutionalized. Without that, anything that we do in deinstitutionalization actually works tremendously against the handicapped. We must, at the same time that we place children in natural settings, recognize that those natural settings need adaptations, too.

Thank you very much, Senator.

[The prepared statement of Dr. Haring follows:]

EFFECTIVENESS AND COST-EFFICIENCY OF EARLY INTERVENTION WITH HANDICAPPED CHILDREN

Presented by
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Seattle, Washington
April 30, 1981

Introduction

Thank you for the opportunity to present testimony before this group concerned with programs for the handicapped. Through my long involvement with interdisciplinary and interrelated programs in personnel preparation, research, service delivery and educational programming for the handicapped, particularly in the area of early childhood/special education, I would also like to express my personal appreciation and that of numerous colleagues from different disciplines for the opportunities we have had to extend our knowledge and to share it with others who seek to understand the complexities of handicapping conditions, child bearing, child development and child rearing. In recent years, it has been gratifying to note the support of our efforts at both state and national levels regardless of changes in administrations. Our record of progress and our focus on wellness as well as illness, on prevention as well as remediation and treatment, on the development of effective and cost-efficient interdisciplinary approaches to problems that have plagued all peoples for centuries has been admired and appreciated in all of the enlightened world. We have clearly demonstrated and documented leadership in dealing with the complex problems presented by handicapped populations in our society.

The leadership the United States now enjoys in the understanding of and provision for handicapped individuals in society has, in large measure, resulted from the government's investment in and support of programs that helped trainers, researchers and providers of service and educational programs realize that no one discipline or agency could begin to impact the many facets and problems presented by the handicapped. Nothing short of national effort can impact pervasive problems with which all must cope.

Those professionals who have had opportunities to be part of these programs and networks have greatly extended their own knowledge and the knowledge relevant to their different disciplines and to our common concerns. The various programs and activities in our Child Development and Mental Retardation Centers or in our University Affiliated Programs have generated new interest and enthusiasm for study, research and dissemination of knowledge about birth defects and their possible prevention and treatment. Our own enthusiasm and interest are heightened by the patronage of the people in our communities and by the many visitors from other programs and countries who are as eager for new, applicable knowledge and technology as those of us who work in these interdisciplinary settings. About ten thousand people annually visit our Center in Seattle. How better can we create public awareness and interest in the advancement of knowledge about handicapping conditions than through this and other forms of dissemination?

Birth Defects

When a baby is conceived, it is the beginning of an incredibly complex and delicate process. From the very moment of conception, cells are dividing and differentiating until nine months later a complete small human being is born.

> Most babies are born whole and healthy, but tragically not all of them come into the world with their full genetic potential.
>
> We know some of the causes that result in less than perfect babies. We know that one or more of the baby's genes may be abnormal or that an extra chromosome may be present, or that hazards in the environment of the mother or unborn baby may be causative factors. (Smith, 1979, p. 37)

It is indeed sobering to consider how many "unknown" causes contribute to the population of handicapped and at-risk infants. The specific causes of risk conditions, however, are less important than the incidence of the conditions, that is, the frequency at which certain conditions occur per numbers of infants. Incidence figures may be expressed in terms of occurrence per numbers of births. For example, the incidence of Down's syndrome is usually expressed in terms such as one in every 700 live births or 1:700. Incidence is also reported in other ways, such as incidence of different categories per 100,000 live births. Present figures of incidence of certain handicapping conditions are presented in Table 1.

In contrast to incidence figures, prevalence figures refer to the total number of individuals in the population having particular handicapping conditions at a given time. Prevalence figures are useful because they give us a global picture of health and service needs, but they are even more difficult to ascertain than incidence figures because of the many factors that affect a given population. For instance, many people considered to be mildly retarded during their school years -- because of their difficulties in coping with school-related activities -- are able to function adequately in adult life outside of school; thus, these people are likely not to be included in the estimates of the prevalence of mental retardation. Furthermore, as medical sciences expand the life span of human beings, prevalence of handicapping conditions will increase.

Professionals restrict most of the discussion to incidence, because incidence figures are more accessible than prevalence figures; most records are based on reports of incidence. However, we must stress that the incidence figures for many conditions represent only the tip of the iceberg. Many infants are not brought to the attention of screening programs, others may not be identified if they do not require clinical services, and still other children with deficiencies cannot be identified until a later time when the particular deficiency becomes apparent. Furthermore, handicaps which result from childhood traumas, illnesses and accidents are not included in incidence figures, but these injuries add to the prevalence figures and to the numbers of children who will require special services. Only when we begin to base our service estimates on prevalence figures, instead of incidence figures, will we really begin to serve the handicapped children and young adults who require our attention. And it is only through continued child find services, funded in part by federal monies, can we expect to compile accurate prevalence figures.

Even the incidence figures presently available are conservative and limiting when efforts are made to predict how many infants and children will need special services and programs. Variations in these figures arise for various reasons: some reports include children from birth to five years; others from birth to three, birth to two, or three to five years. Moreover, legal definitions of some types of disabilities also affects the figures.

The wide range of data sources indicates the problems posed by vague and overlapping definitions of disabilities, variations in reporting systems and gaps in descriptive data for many populations. Incidence figures probably remain the educator's most useful tools to estimate needed services for "at-risk" infants and their families. However, professionals have long recognized that the availability of services or the lack thereof also impacts on reporting procedures. The need for clearer definitions of handicapping conditions and for uniform data collection and recording systems should

Table 1

Incidence of Handicapping Conditions with Prenatal Onset

(Estimated 9,306 Cases Per Year)

Handicapping Conditions		Incidence Per 100,000 Births
A.	Primary abnormalities of the central nervous system (CNS) - 2,700 cases estimated	
1.	Anencephaly	21
2.	Spinal bifida	42
3.	Congenital hydrocephalus	16
4.	Others	11
	TOTAL CNS	90/100,000
B.	Syndromes - 6,606 cases estimated	
1.	Down's*	38
2.	Autosomal	4
3.	X-linked	1
4.	Other specific syndromes	1
5.	Multiple congenital anomalies	25
	TOTAL SYNDROMES	69

SOURCE: Congenital Anomalies and Birth Injuries Among Live Births: United States, 1973-74. Vital and Health Statistics: Series 21, U.S. Department of Health, Education and Welfare, Public Health Service, Office of the Assistant Secretary for Health, DHEW Publication No. (PHS) 79-1909.

*This represents a very low estimate; the actual number of Down's cases per year is closer to 3,303 or about 1:1,000. These cases probably represent one half the total number of births in the syndromes category.

stimulate coordination and cooperation among agencies and the different disciplines in order to increase current knowledge and understanding of factors influencing learning and development. At the present time, we have no national registry or consistent way of reporting incidence, prevalence or indicating the numbers of handicapped for whom services are provided. All professionals, planners and legislators would benefit from the development of consistent and comparable reporting mechanisms.

Developmental Disabilities

The epidemiology of handicapping conditions, like the epidemiology of disease, includes the study of correlates, as well as determinants, of developmental disabilities. Risks continue to be discovered, some relating to natural histories and others to socioeconomic and environmental variables. Thus, epidemiology provides the broad understanding of handicapping conditions necessary for planning services to high-risk and handicapped infants. When risk factors are clearly identified, primary prevention is possible. This prevention includes prenatal care, genetic counseling for high-risk parents and nutrition programs for infants and mothers.

The need for these preventative programs has been demonstrated. The 1979 Early Childhood and Family Development report, for example, states that about 34,700 women who gave birth in 1975 did not receive prenatal care; about 20.1 percent of babies born to these women were classified as low-birth-weight infants, while only about 7.4 percent of all infants at birth were low-birth-weight (p. 23). Primary prevention, through prenatal care, should have been available to these mothers, and secondary prevention and screening efforts should be directed at their vulnerable, high-risk low-birth-weight infants. Finally, tertiary prevention or rehabilitation is needed to develop the abilities of those at-risk children who finally are diagnosed as developmentally disabled.

A timely research study by Charlene Behrns in Washington state points to the discrepancy between services needed and services provided. According to Behrns, "There are a substantial number of persons ages 3-5 and 18-21 who are not involved in special programs, even when the most conservative estimates are used . . . The count of pupils with handicapping conditions in the public schools in the state of Washington appears to be correlated to the available funds, legislative controls and the reporting requirements peculiar to fiscal channels" (Behrns, 1979).

Rather than the numbers of eligible at-risk or handicapped children, funding limitations determine the numbers of children served. Unfortunately, this is not an isolated problem. The December 12, 1979 Report on Education Research describes a U.S. Office of Education report stating that "about half the states are serving 8 percent or more of their school-aged population as handicapped, (while) many states are below this figure." Depending upon whether learning disabled students are considered in the count, national estimates show that 10 to 12 percent of the school-aged population need special education or related services (Martin, 1980).

One has only to read a recent book by Seymour B. Sarason and John Doris entitled, Educational Handicap, Public Policy, and Social History: A Broadened Perspective on Mental Retardation, to realize that. Mental retardation is much more than a mere clinical entity, for it is not comprehensible unless considered in relation to American society, culture and history. It would no doubt be productive to review this background and to consider their perspective in relation to other handicapping conditions in planning future directions based on new knowledge and research, to shift the requisite of service from legislative control to identified needs.

Through federally funded projects and networks, there have been unprecedented advances made in our understanding of and work with handicapped children and youth over the past twenty years. The road to progress, however, is never smooth and in the beginning there was an unbelievable amount of work to be done in just determining the nature and scope of the problem with which we were dealing. Efforts to gather accurate

data on numbers of handicapped children and youth needing services were complicated by reluctance on the part of states and school personnel to find and/or report such information because of budget obligations.

The editors of Closer Look (a project of the Parents' Campaign for Handicapped Children and Youth) suggest in their December 1978 issue some problems in achieving accurate counts of handicapped children. Among these are the following: (a) some school districts with insufficient budgets to provide appropriate services are reluctant to admit this inability and their consequent noncompliance with Public Law 94-142, and therefore do not count all handicapped children; (b) states in turn do not report these unserved children; (c) dates on which children must be counted have led to mechanical problems in catching within the net all children needing services; (d) there are insufficient numbers of trained specialists to identify all children needing services; (e) children leaving elementary school become "part of a forgotten population" because there are not enough programs to serve them; (f) preschool and nonpublic programs often remain uncounted; and (g) parents, "among the best sources of information about the whereabouts of handicapped children," are often not invited to participate in child identification efforts (p. 8).

Some of these factors no doubt contribute to the following statistics cited by the Council for Exceptional Children in their publication, Exceptional Child Education at the Bicentennial: A Parade of Progress (1977): "Currently, only about 40% of school aged handicapped children receive appropriate specialized educational services. The estimate for preschool children is only about 25%" (p. 93).

In some areas where Child Find has reported only a small number of handicapped children, some concerned professionals have contacted physicians, other professionals, hospitals and parent groups and have frequently turned up five or ten times the number of children reported by Child Find. In situations where certain numbers of children were required for initiating services, we were often unable to find the required number. However, when services were made available, we not only found the numbers required but two or three times as many children.

The Severely Handicapped

Developing programs for severely handicapped persons has become the challenging responsibility of educators. While it would be foolhardy to insist that educators alone can or should implement programs designed for severely handicapped persons, this fact remains: as a result of recent legislative mandates, court decisions and accompanying social trends for change, educators are now on the front line in efforts to change centuries of neglect and mismanagement of severely handicapped persons. In fact, they are the only professionals required by law to be there (Haring, Hayden & Beck, 1976, p. 1).

Many public schools do not provide early intervention programs for handicapped children, and thus these public schools receive many handicapped children who have not had the benefits of an early intervention program that prevents and remediates some of the primary and associated or secondary handicapping conditions before the children reach school age. The problems some of these children bring with them to the public schools are indeed difficult to deal with at the kindergarten or primary grade levels.

Beginning in 1974, we were funded to conduct a study in collaboration with the Seattle Public Schools' Special Education Department on "The Acceleration and Maintenance of Developmental Gains in School Aged Down's Syndrome Children." The study was conducted over a period of six years (1974 to 1980). We followed up the children who had been in the program for Down's syndrome children at the Experimental Education Unit (EEU), Model Preschool Center for Handicapped Children, and maintained data on a comparison group of age-matched Down's syndrome children who had not been in the EEU program. In addition, we worked with Seattle teachers who were serving a contrast group of older Down's syndrome children who had not been in our early intervention program.

The EEU children who had the benefit of early intervention have consistently maintained their developmental gains and demonstrated higher levels of performance than either the children in the comparison or contrast groups.

By working with teachers and applying the best we knew about teaching children with Down's syndrome, we were able to bring the contrast group to a level of functioning equivalent to that of the EEU Down's syndrome children. It should be pointed out, however, that the average or mean age of the children in the contrast group was three years older than the children in the EEU group who had received early intervention at a far less cost than the children in the public school program. Also, the children in the contrast group had developed many inappropriate behaviors that interfered with learning; these behaviors had to be decelerated before these children could make any progress in academic achievement areas.

We need to consider the problems we are asking teachers to assume who work with handicapped children who have not had the benefits of early intervention programs. We must also consider differences in costs as well as the delayed progess of older handicapped children who will need to be served in special class programs throughout the period of their schooling.

Are We Being Short-Sighted?

A basic problem is that children's needs do not fit our budgets. Do we really want to know just how good or how bad a job we are doing, or do we want to continue to offer excuses and raise questions that detract attention from our piecemeal, too-little-too-late, penny-wise-and-pound-foolish, exclude-rather-than-include approach to solving these problems?

Through well administered, carefully evaluated and monitored federally funded "seed-money programs" for early intervention with handicapped children and their families, we have definitely demonstrated the replicability as well as the effectiveness and cost-efficiency of the model Demonstration, Outreach and State Implementation Grant programs funded through the Handicapped Children's Early Education Program (HCEEP) of the Office of Special Education, U.S. Department of Education. In addition, these programs have done much to extend services to formerly underserved or unserved handicapped children and their families.

The 100 HCEEP projects funded during 1980-81 provide services to over 2,849 children and their families, train other service providers, develop curriculum and assessment instruments and disseminate information to the field of early childhood special education. Outreach projects so far have trained over 25,000 persons and established 640 replication sites serving 18,400 children. State Implementation Grants (SIGs) have been effective in increasing the numbers of children served by State Education Agencies. From 1976 to 1979, for example, services in Arkansas increased 398%, in Alabama, 275%, and in Indiana, 228%. Furthermore, with SIG influence, 38 states showed an increase in the numbers of preschoolers being served. The SIGs have also encouraged interagency cooperation and ensured that State Education Agencies provide programs and support for early childhood education.

Because these federal programs are closely monitored and carefully evaluated, the services, curricula, assessment instruments and information from these programs have been of consistent high quality. So far, 19 projects developed with HCEEP funding have been approved by the Joint Dissemination Review Panel of the Department of Education on the basis of evidence of effective programming for children (Assael & Harrison, in press).

As director of an HCEEP Demonstration and Outreach program from 1969 to 1980, I can certainly testify to the rigor exerted in the evaluation and follow-up of these programs. In addition to both internal and external evaluations by outside evaluators such as Abt Associates and Battelle Institute, Columbus, our project received annual site visits

from representatives of the funding agency itself; moreover, we were required to submit data on child progress, program effectiveness, and cost-efficiency, to present before the Joint Dissemination and Review Panel and to be reviewed by the National Diffusion Network: these programs have indeed been put to test. We would not have had it any other way, because the value of these and other federally funded programs must be justified and recognized. These programs pay for themselves many times over in preventing, remediating and permitting ongoing assessment of handicapping conditions in young children.

An abstract of a follow-up study of children served in the Model Preschool Center for Handicapped Children (Appendix A) shows the benefits of our own early intervention as these children went out of our programs into programs in their own school districts. Other such studies provide similar findings on the ability of many children served in early intervention programs to move successfully into regular classrooms. Early intervention with handicapped children and their families is far more productive, effective and cost efficient than delaying such intervention until school age and thus compounding problems not only for the individual child and his or her family but for professionals and society as well.

HCEEP Demonstration Programs: Continuation and Sources of Continuation Funding

The Handicapped Children's Early Education Program (HCEEP) is a federal seed-money program that sponsors the development of high quality service-delivery models for handicapped children and their families (Swan, 1980). Through HCEEP, the federal government supports Demonstration projects for a three-year period, during which time the projects develop from an initial service concept to comprehensive, self-sustaining programs which other interventionists may adopt in full or in part. The success of this seed-money program depends, in part, on how well individual demonstration projects become self-sufficient and in the numbers of handicapped children these projects continue to serve once federal funding ends. Three studies have been completed since the program's inception in 1968 with the passage of P. L. 90-538, the Handicapped Children's Early Education Assistance Act, and these studies show that the success rate of these demonstration programs is about 89.6% (see Table 3).

A study of 21 demonstration projects in the first cohort of HCEEP found that 18 projects (86%) continued in some form (Swan, 1980). Moreover, of the continuing projects, ten projects (47%) expanded their services to include children with more types of handicaps; twelve projects (57%) expanded to serve more numbers of children. A later study (Daniel & Jackson, 1980) of 17 HCEEP demonstration projects showed that all 17 (100%) continued their services after their three-year period of HCEEP funding expired. Of these 17 projects, ten (59%) continued full services or expanded their services (Table 2), either adding new components, serving more children, or serving children with wider ranges of handicapping conditions. Nine of the 17 projects (52%) increased the numbers of children served, while four (23%) served the same numbers of children as they had during the HCEEP funding period.

The most recent study of HCEEP demonstration projects (Cox & Taylor-Herschel, 1981) showed that 44 of 53 HCEEP demonstration projects surveyed (83%) continued at least some components of their model after their funding expired. Of these, 13 projects (24.5%) offered the same services or expanded their services; 35 projects (66%) were still offering at least 70% or more of the services they had provided during their funding period.

Taking these studies together, 89.6% of HCEEP demonstration projects continue to offer at least some of their original services after leaving HCEEP. Moreover, 30.8% of

those projects actually increase their services to handicapped children and their families. In some cases, projects increase their services to qualify for funding from particular sources.

With continuing and in some cases expanding services, how are these projects maintaining their financial base? Each of the three studies answered this question in part, and each study found that most of the continuation monies comes from local agencies (Table 2). Of the 21 projects studied by Swan, 18 projects were drawing upon 16 sources of continuation support, including local education agencies, state education agencies, United Way, universities, fees, developmental disabilities agencies and other sources. Thirteen of these 21 projects (61%) received direct funding from local education agencies (LEAs), but only two projects (1%) received money from LEAs alone (Swan, 1980). Fifteen of the 18 projects had a multiple-funding base of two or more sources.

Daniel and Jackson (1980) found that 11 of the 17 HCEEP projects (65%) they studied received continuation funding from two or more sources. The most common source was the LEAs which partially funded ten (59%) of the 17 projects. Seven projects (41%) received money from other local agencies such as mental retardation centers, university medical centers and preschool developmental centers. Fifteen projects (88%) received some kind of state funds, and eight projects (47%) received some kind of federal funds, including Title I, Title I Migrant, Title IV and P. L. 94-142 monies, filtered through various agencies. Table 2 compares the general funding sources and percentages of projects receiving money from those sources.

Cox and Taylor-Herschel (1981) had results similar to the above-mentioned studies. Thirty-six of the 53 projects they surveyed (68%) had multiple-funding bases, half of which used three sources or more. LEAs again accounted for the majority of money, funding 16 (31%) of the projects, while other local agencies funded ten projects (19%). Local agencies, then, funded 26 (50%) of the projects, followed by state agencies which funded 22 (41%) of the projects. Other sources, accounting for funding to five (9%) projects, included private foundations and trusts, the National Institute of Mental Health, Maternal and Child Health, Indian Health Services and fees for services.

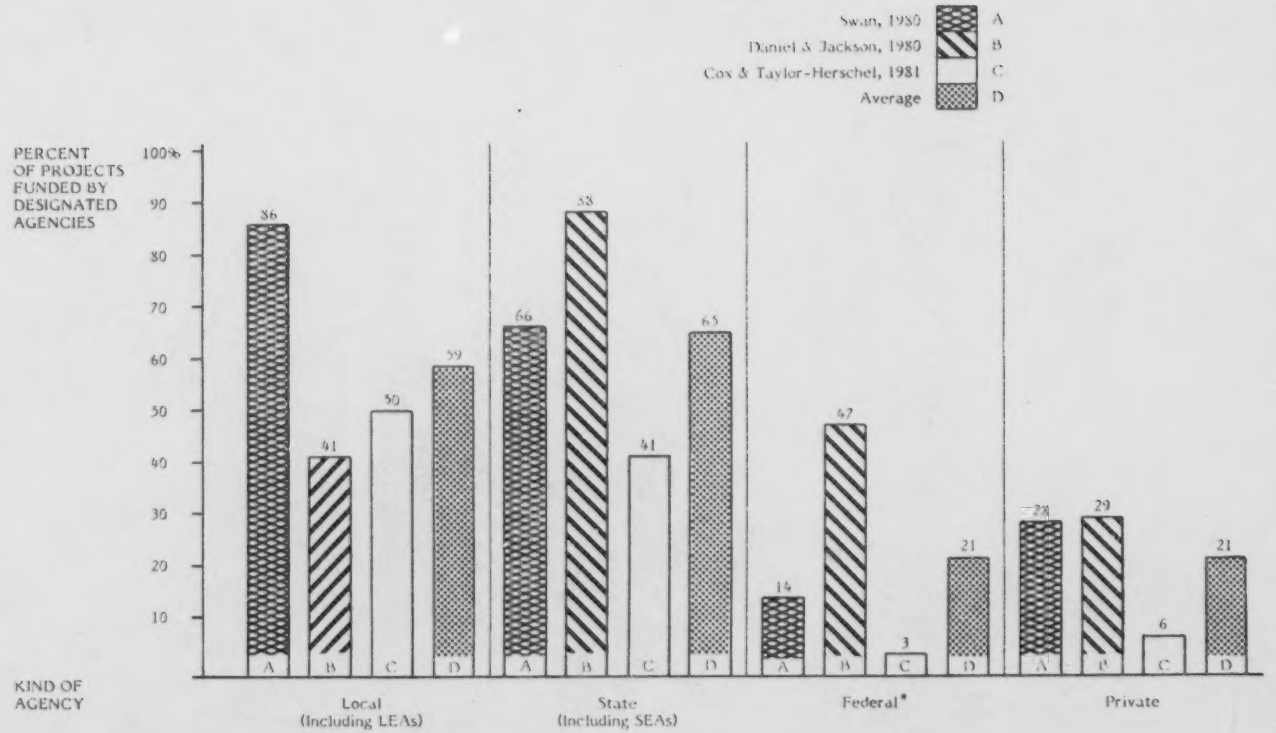
Thus, HCEEP demonstration projects have not only been successful in continuing or expanding their services to handicapped children and their families, but they have succeeded in finding broad bases of financial support for the continuation and expansion of their programs. As reported by Cox and Taylor-Herschel (1981), this success is "due to the HCEEP funding that allowed (these projects) to document the need for local services, establish parent and community support, develop and implement demonstration services for children and families, and develop a good reputation" (p. 5). The federal seed money made available through the Handicapped Children's Early Education Program gives demonstration projects the financial support they need to secure community support; with this advantage, projects can survive, even thrive, in their continuing effort to serve the handicapped children and their families in the United States and in other nations.

Cost-Effectiveness

A major justification for any program is, of course, its cost-effectiveness. While numerous studies are available which show the relative costs of programs within specific areas (Stock, 1976; Macy & Carter, 1980; Pennsylvania Department of Education, 1978), no nationwide study has so far been published. Nevertheless, Mary E. Wood, in a paper soon to be released from Western States Technical Assistance Resource (WESTAR), has collected various cost-effectiveness data from single studies throughout the United States in order to estimate the average costs and the cost savings of early intervention programs (Wood, in press).

Table 2

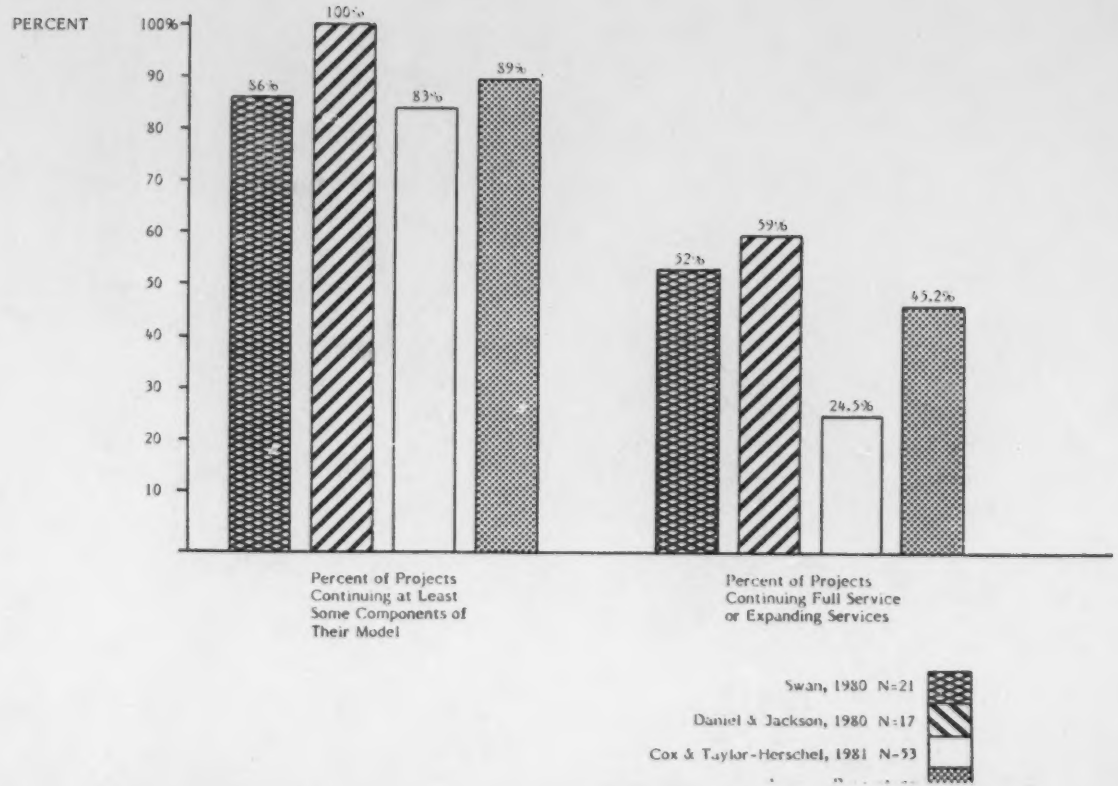
Sources of Continuation Funding



*Includes monies from DPP, NIMH, Maternal and Child Health, Title I, Title IV and P. L. 94-142 available through state agencies and institutions. Preschool Incentive Grant monies were excluded in this category from the Cox & Taylor-Herschel study and were included in State monies.

Table 3

HCEEP Demonstration Project Continuation



Collating and averaging cost data from the Texas Consortium study of 806 children aged birth to two years (Macy Research Associates, 1978; Macy & Carter, 1980), a National Diffusion Network (NDN) study of special education programs from seven states (Far West Laboratory for Education Research and Development, 1979), the Battelle Research Institute study of the Handicapped Children's Early Education Programs (HCEEP) and various state education cost surveys, Wood found that the costs of education for handicapped children increase as intervention with the handicapped children is delayed. The younger the child at the time intervention begins, the greater the savings over time in his or her educational programming.

Wood computed the median costs of special education per child per year as $2,021 for infants, $2,310 for preschoolers and $4,445 for elementary and secondary students (Wood, in press; Table 4). These costs compare with the median cost of regular education per child per year of $1,148 for all age groups. Because children who receive early intervention frequently enter regular education programs, those children who receive intervention early will, in the long run, require less expenditure of funds for their education; rather than requiring the $4,445 per year for special education in primary or secondary school, a child who receives early intervention and enrolls in regular education will cost taxpayers only $1,148 per year.

Table 6 shows the average attrition rates into regular education per age group, and Table 5 shows the total special education costs at 1978-79 levels per child over an 18-year period begining at birth. Both tables show that the costs for the full 18-year period for children with whom intervention begins at birth is $37,273. If intervention is delayed until age two, these costs increase to $37,600 and if intervention is delayed until age six, the costs increase to $46,816 or $53,340 depending upon whether or not the child enters regular education. Thus, there are substantial savings to taxpayers when children receive intervention at least by age two, and maximum savings when intervention begins at birth. Because attrition into regular education is cumulative over time (see Table 6), expanding services to preschoolers and infants means increased savings over time. Table 3 shows the estimated numbers of children receiving special education services over time, based on populations of 1,000 students, and the average attrition rates from Wood (in press).

Funding

Providers of early intervention programs for young handicapped children and their families are concerned that proposed budget cuts and recision together with consolidations of programs into LEA and State Block Grants will mean that many handicapped children will not be identified or will not receive early intervention services and educational programs essential to the prevention and remediation of primary, secondary or associated handicapping conditions that could be treated and alleviated in the early months and years of these children's lives. It is neither moral nor ethical to withhold treatment that could prevent, remedy or alleviate handicapping conditions that will otherwise add to the individual's burdens and limitations throughout his or her lifetime. Such withholding may also greatly limit the independence and contributions these individuals might otherwise make to society. Some handicapped individuals are intellectually or otherwise gifted; history is replete with case studies of the great contributions such individuals have made in various fields such as art, music, science, medicine, literature, education, social sciences and politics.

As indicated in previous pages of this testimony, state and other local funding sources have already been heavily utilized in the continuation of demonstration programs and the provision of needed services for young handicapped children. Cuts in state

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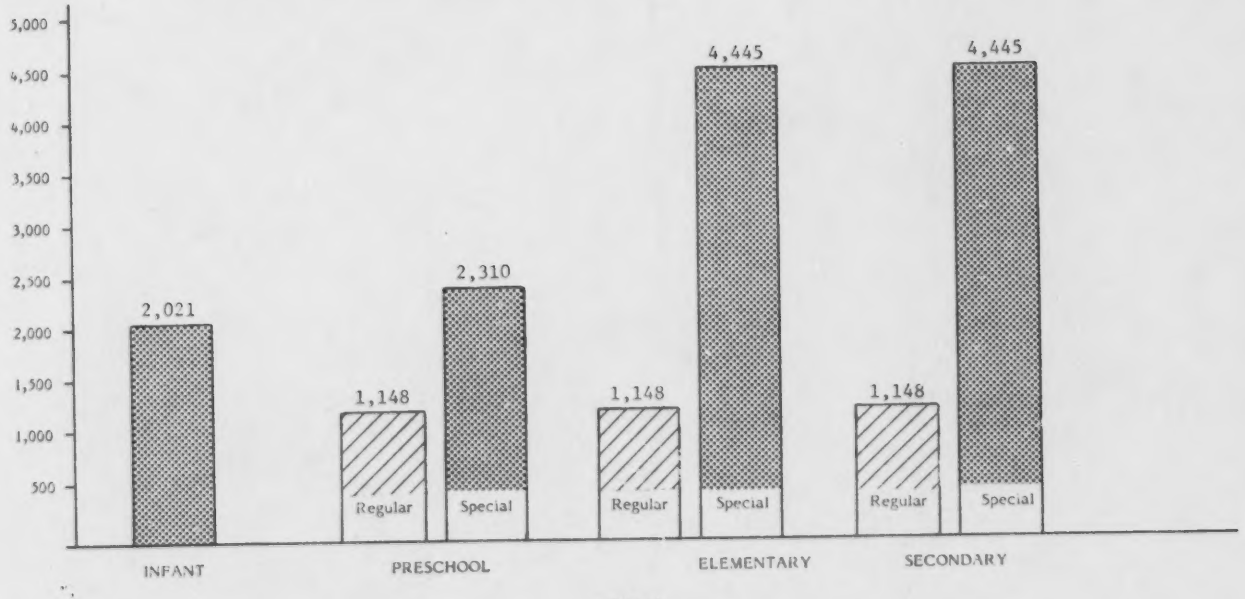

Table 4

Median Cost of Special Education

Per Child Per Year

(12 Months)

(1978-79 figures)

Regular Education

Special Education

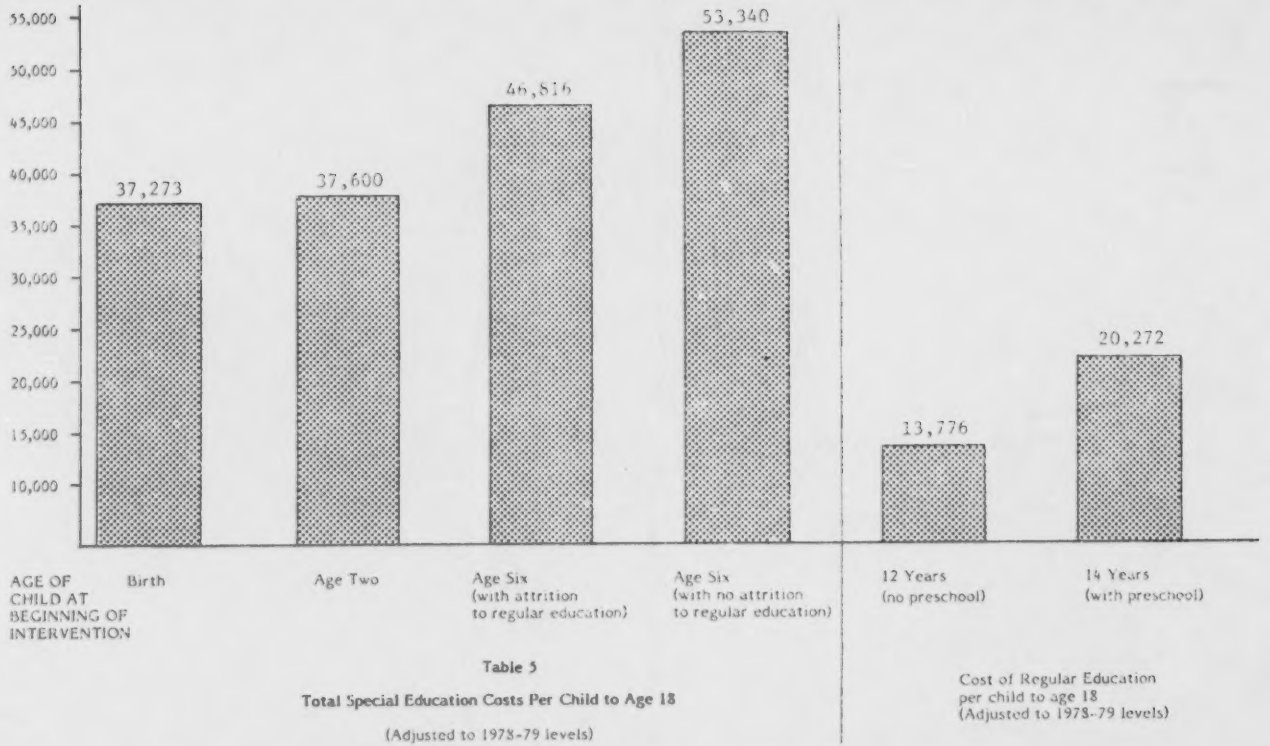

Table 5

Total Special Education Costs Per Child to Age 18

(Adjusted to 1978-79 levels)

Cost of Regular Education per child to age 18 (Adjusted to 1978-79 levels)

(Based on study of 940 multiply handicapped children, ranging from severely to mildly mentally retarded)

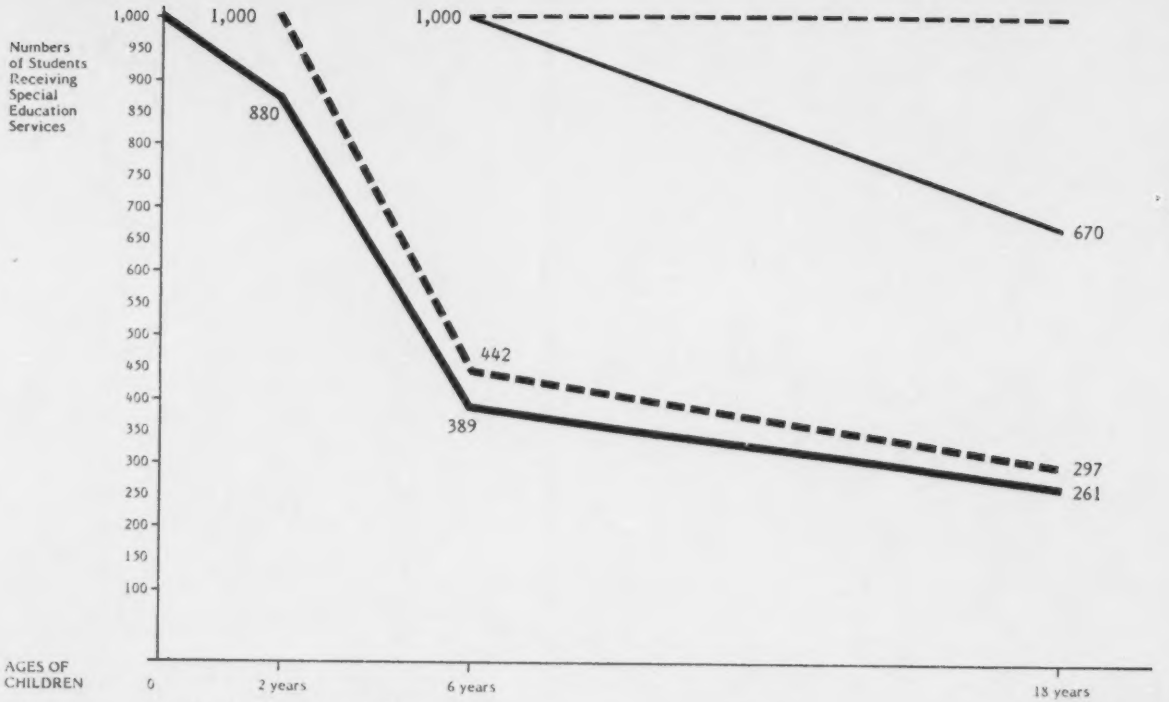

Table 6*

Comparison of Costs of Special Education

As Intervention is Delayed

budgets may reduce some of the funding that has been received for these programs. Local education agencies and state education agencies have had sharp cuts in their budgets.

Monies made available through Block Grants are to be used for any one, some or all of the formerly targeted purposes. Groups that worked to cooperate and coordinate programs in the past will be pitted against each other in seeking funds for special programs.

Many special educators recall that when some monies from Title III could be utilized for handicapped children, the total amount spent never rose beyond three percent until there was a mandate requiring that at least 15 percent of those funds were to be spent on special education.

While we realize there are no easy solutions to reducing budgets, we urge that great care and discretion be exercised in order to avoid drastic and devastating reductions in much needed programs that have demonstrated effectiveness and cost-efficiency.

The information available to date about proposed reductions, recision and consolidation of programs through Block Grants give parents, professionals and the public no assurances that there is realistic recognition or understanding of the problems in our communities and states as we seek to deal with the needs of children and youth in early childhood/special education programs and in the provision of special education services and programs for school aged children.

Cooperation and coordination is essential if we are to make the best use of the human and financial resources available. The progress that has been made in the past ten or twenty years is little short of remarkable, but there is much that still remains to be done. There are yet many unserved or underserved children who desperately need the assistance that we could provide to make them more independent, useful and productive citizens in our society.

The administration of programs is time-consuming and expensive at any level. In this, the International Year of Disabled Persons, and in the continuing conduct of national effort on behalf of the handicapped, we cannot afford to abandon our efforts to coordinate and disseminate information about the progress that has been made in serving these various populations of children, youth and adults. Neither can we afford to disperse and divide responsibilities for various aspects of the program to different agencies in national or state governments. We cannot afford to refuse opportunities for national and international leadership in any field. We have developed effective and cost-efficient programs, strategies and technologies that benefit handicapped children, youth and adults in our own country that can be shared and utilized effectively in other countries as well. We all share the problems of the handicapped, for the prevalence of these conditions is so widespread that no one can isolate or protect himself or herself from close contact with or the possibility of having some personal impairment at some point in life. The sharing of our "know-how" in this area that may be important in our own personal, family or friends' lives in this or other countries is no doubt the least expensive and most helpful and effective way of creating good will around the world.

(Note: In the interest of economy, the appendix to this statement was retained in the files of the committee.)

Senator WEICKER. Dr. Haring, thank you very much. I might add that I think you have made several very, very good points, both as to early intervention—the other things which you touched upon, which I think is important to note throughout these hearings, is the difference between spending and investment. I think there is no distinction made in this town at this time of the investments that we make with Federal dollars, which in fact bring us back more than we spend, or save more than we will prospectively spend. On the matter of just spending, and on the matter of early intervention, I could not agree with you more.

John DuRand, president of Minnesota Diversified Industries.

Mr. DURAND. Thank you, Mr. Chairman.

I am here today to speak to a very narrow area of concern, and that is work for individuals who are developmentally disabled.

Through the support of a DD grant in 1975, we were able to conduct some basic research in the area of employment. We operated on a premise that first, everyone needs the opportunity to work and that the individual's disabilities will only dimension what he does in the area of work, but should not be used to discriminate totally that some people will work and others will not.

The first major issue that we had to deal with was, unfortunately, the public and their perception—not only how they perceived individuals who were developmentally disabled, but what their expectations were—because that public perception and expectation transferred to the future employers, and to those individuals who will be making appropriations.

I have some slides that I would like to use at this point, to demonstrate what is meant.

The programs that we saw this morning, are typical of the way we think of individuals who are developmentally disabled. We categorize them as individuals who are dependent and needing the support of others to exist, rather than looking at them in other dimensions, where some of them are able to become involved in activities as you and I do, that have vocational relationships.

The media in its attempt to bring us total information sometimes give us distorted views, even though it is a real situation that exists. The impact on the public is to see these individuals as totally limited and dependent persons.

Now, we have not yet gotten the level of cooperation from the media that we need to help demonstrate and show the public that these individuals can be productive within normalized settings.

Then for us as professionals, we do things in the configuration of services that we develop that affect public perceptions. And I would ask each of us to just ask ourselves what are our perceptions of individuals who would live there [State institution] and what are our expectations, and at the same time, what are our perceptions and expectations for individuals who would live in a home within our local neighborhood.

Here, we have a group of adults at midday, during a normal workweek, passively engaged in no activity at a pony farm—a totally inappropriate activity—as opposed to two adults who are engaged in horseplay at a company picnic.

The perceptions that the public get from seeing adults boarding orange schoolbuses, "going off to work", in developmental centers

or activity centers, and not only the public, but the future employers are seeing these individuals. What are their perceptions, as opposed to these two adults going to work riding on Metro transit buses?

Put yourself again in the place of a potential employer, and view these individuals in the setting where they are presented here, as opposed to this setting, using the latest technology, to allow them to be productive and engaged in our commerce and industry.

Or this individual—let us not cure him, but let us merely transport him into another environment, an environment that can change how we think, how we feel, and will dimension how we will plan and configure services for him.

Or these individuals, into an integrated work setting within a normalized factory.

Because we wanted to address ourselves to these specific issues and how the public viewed and the way they perceived and what they were planning, we decided that our effort would be based on the fact that we would have a normalized setting. No. 1, we leased facilities in an industrial condominium complex, along with 13 other industrial firms, rather than building a building or taking over an old schoolhouse. Our first priority was to establish a new perception of this company, Minnesota Diversified Industries, a provider of quality service and product to industry. One of our first contracts—and the basic element that we used for selling is the fact that we have a mixed work force, where we not only employ individuals who are developmentally disabled, but also, competent technicians and craftsmen—was to produce microparts for the computer manufactured by Univac for military use.

During the first 3 years of this project, we produced over 3 million units, with only one lot being rejected, and that was because of some problems with the insulation. The QC standards have been met in all cases where we have Federal inspectors within the plant, so we have demonstrated that we can work in areas that, before this, had been pretty well excluded as an opportunity for individuals that are handicapped.

In medical products, we are making external devices used with chronic pain patients. We are serving as a pilot plant for MedTronics for many of their medical products that they are bringing on line for the first time, integrating the latest technology.

The remanufacturing and service of equipment for Western Electric and Bell Telephone, updating and modernizing it, putting it back into service—we are doing the testing and the quality control of their equipment for them, using the services of the developmentally disabled and nonhandicapped employees as a single integrated work force.

We are manufacturing subcomponents for other electronics industries, such as these audio jacks.

We fabricate wood furniture.

And we produce all of the stamp packets that the U.S. Postal Service sells to stamp collectors each year, somewhere near 3 million units, using this same integrated work force.

Mr. Chairman, I believe that through the support of developmental disabilities, we are not only providing these individuals with work, but a whole new lifestyle. And I really think that it is our

intent not just to keep them busy, but to give some meaning in their lives. Through our efforts and the sharing of information, we have been able to assist in other States. Although we have had requests for service in 13 States, we have only been successful in 2. In the State of Georgia, the developmental disability council asked for permission to deviate from the four priority areas, and with our assistance, established two affirmative industries, as we have identified this type of operation, one in Valdosta and one in Cartersville.

The other States that have requested this service have not been able to find support within other services or within other Federal or State programs, because of their limitation in scope. It is because of the flexibility of these Federal D.D. funds and the discretionary ability that has been left with the local citizen boards that we have been able to succeed in Minnesota and in the State of Georgia.

Thank you.

Senator WEICKER. Thank you very much for a very, very graphic presentation of many areas that we really do not think about, but obviously of which are important.

I could not help but think—just the settings, the surroundings, the architecture, the esthetics, et cetera—what a difference it does make in your perception.

Mr. Jerry Provencal, director of the Macomb-Oakland Regional Center.

Mr. PROVENCAL. Thank you, Mr. Chairman.

I would like to say that I am very proud to be here, and I hope that my remarks can help in some way.

I am the director of the Macomb-Oakland Regional Center which is one of 12 State institutions within the State of Michigan. I would like to, if I may, trace lightly the chronology of the development of the institution, tell you where it is today, and share with you what the impact has been on the residents there.

The Macomb-Oakland Regional Center services developmentally disabled people exclusively and is, as I said, one of 12 in the State. We have the catchment area about 2 million people who are in the metropolitan region just north and west of Detroit.

The agency was created by statute, by law, in 1972, and the initial objective was to build a new institution to service the people in that area north of Detroit. The intent was to build an institution that would house and provide programs for some 750 people who are mentally retarded. From the particular region that we now service, we had about 1,500 individuals who had moved to out-State institutions before this new institution was to be constructed.

So it is important to understand that the intent in 1972, the grand design, our "hope" was placed in the building of a brandnew institution that would house and provide programs for 750 people. At about the same time the architects were working on the design of the facility, we applied for a Federal Vocational Rehabilitation Services demonstration grant, with the objective of receiving enough funding so that we could hire some staff that would find alternatives to the institution, that could find and develop community placements and corresponding support services. The grant was a rather modest grant, a little over $100,000 a year for 3 years.

The pointed objective was to move 100 of the 1,500 individuals residing in the out-State institutions back each year to the local community, to the larger community, from which they had come for the 3-year life of the grant.

We had high hopes for the grant, but we really did not realize at that time just how successful we would be, and I would like to share that success with you at this time.

When we began in 1972, there were no group homes in the region I am from; there were none. Today, there are 94 small group homes that service and provide housing for 6 people or less. In 1972, there were no specialized foster care homes, where one individual would move in with a family and receive programing, housing, supervision, and so forth. Today, we have over 200 of those specialized foster homes.

At that time, again, we had 1,500 individuals who were mentally retarded living in institutions; today, there are 300. At the time, we had a waiting list at all State institutions, and at our own, over 150 people were standing in line to get into the institution. Today, there are no waiting lists, not only at our facility, but throughout the State of Michigan.

Rather than having parents demanding to have their son or daughter placed within the institution, which was about the only option we had in 1972, today we not only have a variety of community alternatives, housing and support alternatives in the local community, but we can provide services and even cash subsidies to families of clients who are living in their own homes.

The institution that was to be built for 750 people today has 100 people; it never got off the ground for more than 100 because the grant program was going so well. As a matter of fact, today, rather than having an institution for 750, we are now in the beginning stages of a plan to phase out even the 100 beds between the years 1981 and 1983.

It is important for me to point out to the committee that I am not a radical social worker, even though that is my discipline, who is housed in a program that is community based exclusively. I am the superintendent of an institution; it is just one that is quite different from others.

The range of residential opportunities and options that we have for parents really are embellishments on the old group home and foster home concepts. They are not really much different, probably, from those found in any of the other States in the United States.

Primarily, we concentrate on small placements with a lot of individualized attention; they are found throughout all neighborhoods. There is no dumping of people; there has been no ghettoizing of placements. The homes, just as Mr. Durand pointed out, look like anyone else's home in Minnesota. Likewise, they blend into our communities in Michigan as well.

The residents who are living within the placements rather than institution, people who previously never left the grounds, now go to school or vocational programs within their surrounding communities every single day. Residents who previously received all their medical attention in the infirmaries or on their wards now have physicians down the street in clinics, like their neighbors.

Residents who previously spent their leisure hours in dayrooms or in segregated recreation halls now belong to racquet clubs and go to YMCA's, use community pools, and so forth. Residents who previously interacted with neighbors in local communities primarily only on Kiwanis or Rotary pizza days now participate with them locally in every variety of life.

The same residents who previously spent most of their time confined to the institution's grounds now plant flowers and trees in their own yards they paint the interior of their homes, and the outside. They take pride in these things, and although it sounds very trite, they are terribly proud to be neighbors of everyone within the community.

Residents who previously dressed in non-descript or our-of-fashion clothing given to them by institutions now wear clothing that fits, that is not three fashion trends behind, and that is rumpled only if they want it to be, not because an attendant called in sick.

The progress made by the residents in the specialized foster homes and group homes is remarkable it is absolutely remarkable; and it is considered so by parents who had misgivings about placement, by staff who work within the institutions and now see residents after they have moved to the larger community, and by friends, relatives and school teachers. Across the board, it is considered that they have made tremendous progress that could not have been made within the institution. They have changed in appearance and demeanor. They have changed in such things as the reliance upon behavior-depressing drugs; they have changed in all manners of their independence and growth maturity.

A recent survey we are in the process of completing shows that in the areas of adaptive behavior—particularly in self-sufficiency, speech and communications, and the ability of individuals to feed themselves and to take care of other bodily functions—they have remarkably changed for the better.

The homes that I am speaking of, the group homes and foster homes, have staff in each case who receive expert training instruction from professionals. There is a variety of performance criteria required of those people before they work with residents within the homes.

The support and follow-along services that are given to the individuals that live within the community are very, very adequate. We have case manager to client ratios, for example, of 1 to 25 so one social worker would follow services to 25 residents.

We have formalized parent monitoring groups that visit the homes and report on a monthly basis. We have protective and advocacy services as well as licensing agents involved. It is important to point this out because frequently there is an association with community placement, when it is done rather rapidly and on a large scale—and we are only talking about 8 years—there is an association with it being dumping. This is not the case at all at Macomb-Oakland.

Community placement makes the resident more visible to the larger community, and we think that is critical with regard to follow along and guaranteeing that the person is not lost once they move to the community. As a matter of fact, we found that, in some ways, it is kind of embarrassing, because this monitoring does

not cost us a cent. We have found that the best monitoring and the best assurance against abuse and neglect to the person who lives in the community is the neighbor over the backyard fence; they tell us more quickly than almost anyone when something seems to be amiss.

It is critical to point out whom we are talking about. Not only am I talking about residents of an institution or former residents of an institution, but 79 percent of the over 1,000 people who are living within group homes, specialized foster homes and apartments in our area, 79 percent, test in the severe to profound range of mental retardation. So, we are talking about people who have very serious handicaps and secondary handicaps as well.

Within our State, we know that the people who are presently remaining within institutions, functionally speaking, are the twins of these individuals. The people who are still living inside, waiting for a place to come out to, are people who have disabilities that are not that much different from their counterparts in community placement.

Admissions to the institutional system in our particular region are nonexistent. They are admitted to a system which is a community-based facilities system, but not to the institutions. We have no waiting list, as I mentioned. There are no requests for institutional admission anymore. As a matter of fact, parents demand community placement; one even recently threatened to sue me if her son was not quickly admitted to a group home. In the old days, it was the opposite; it was the institution where people pulled strings or made threats to make certain that admission was guaranteed.

Recidivism is almost nonexistent. The only time we really had any considerable recidivism was early in the development of the program; we have had almost none in recent years. As a matter of fact, since 1976, only eight people have returned to the institution and in each case, it was our fault; it was not theirs.

Public support for the program is demonstrated in well over 12 editorials that appeared last year in all the major newspapers, the minor newspapers, the dailies and weeklies in our area, with editorials coming out supporting it. We have found a way to get to the press and convince them of the merits of this program.

Parental support has been across the board; it has been, in the beginning, one that came on the wings of misgiving. Parents were not believers that this program was right for everyone, particularly their son or daughter. Last year, when we needed it, we had 3,000 letters from parents supporting the program, and a large demonstration in our State capital supporting the program.

Legislative support has been good. However, I think that whether you get legislative support or not depends upon many things, not the least of which is the economy and pressure coming from people.

To conclude, I would like to say that I come today not as a parent, but I am the superintendent of an institution that is a little different. I have worked in capacities in the mental health system that ranged from being an attendant, a direct care worker on a ward, through positions as a group home worker, a manager of a group home, a social worker, and now as a superintendent.

I would say that if there is anything that can be done to make it easier to move people who are developmentally disabled out of institutions today and into the kind of life that I have just described in a compressed version, if there is anything at all that can be done, it should be done. Everything that can be done to keep the next generation of developmentally disabled citizens in their home communities and away from the institutions must be done.

Thank you.

Senator WEICKER. Thank you, Jerry, very much.

The next witness is Julia Ewing of Case Management Services. Julia, Senator East wants me to give you his kindest regards. He is delayed at another hearing; he was hoping to be here so he could introduce you himself. So, on behalf of him, I welcome you to the committee and we look forward to your testimony.

Ms. EWING. Thank you.

As the parent of a 19-year-old developmentally disabled son, I am personally aware of the difficulties and frustrations that individuals face in seeking services that require the combined efforts of specialized and generic services. I am not wearing my parent hat today, but it is a very difficult hat to remove, so I want to acknowledge that.

I have been asked to tell you, in general, about North Carolina's case management projects, and specially about the Alamance County developmental disabilities case management system, of which I am the director.

In 1978 the North Carolina Council on Developmental Disabilities selected the Center for Urban Affairs and Community Services at North Carolina State University to identify and survey existing case management efforts nationwide and take the best ideas from that survey to put together a system that would work in North Carolina.

In North Carolina, the case management system is a mechanism for linking and coordinating segments of the service delivery system to insure a comprehensive program for meeting an individual consumer's needs, as well as monitoring and follow-along of that individual. Attached to my testimony is the theoretical base for our case management system, and I will not try to go into that.

The case management system is designed to provide: A single point of contact within the system of human services for the developmentally disabled individual; an assessment of all the developmentally disabled person's problems or needs by a trained professional; a complete plan of services to meet the particular needs of the client; lifetime monitoring and guidance of the client's progress; more time for service delivery responsibilities for service providers, because many administrative tasks are carried out by the case management system; better coordination among service providers; documentation of the needs of developmentally disabled persons; active participation by the client in securing services and care through an open working relationship with the case manager; and reduction of waiting time for the client before service delivery begins.

However, from that theoretical base, 22 months ago the developmental disabilities council established two demonstration projects—one in rural eastern North Carolina, and the other in the

Piedmont, in my county, Alamance County. Since then, there have been three new sites begun that serve eight other counties.

The North Carolina Developmental Disabilities Council believes that these five sites provide enough information about the State and the needs of developmentally disabled people to adapt the case management concept to specific areas.

Alamance County is located in Piedmont, North Carolina. The population of the county is 99,000. The largest city is Burlington with 37,000 people. Textiles is the principal industry.

Alamance County is recognized throughout the State as a leader in the provision of quality services to its developmentally disabled citizens. In my opinion, this is because of a happy combination of determined parents, dedicated professionals, and a concerned citizenry.

Developmental disabilities funds have been used in Alamance County in previous years for the construction of a modern sheltered workship and to purchase a van and a bus to provide transportation to the developmental center and to the workshop.

When the county learned of the availability of developmental disabilities funds for case management services it saw opportunities to try new methods of service coordination, to reach individuals who were not receiving any service, and to begin collecting the data that will eventually give us a better picture of the current and future needs of that portion of Alamance County's population that is developmentally disabled.

The Alamance County developmental disabilities case management system is a part of county government and is under the direction of the county manager. We have no official affiliation with, nor are we housed in any other human services agency. We see this as a distinct advantage, in that we are accountable only to the individual client with whom we are working to seek and coordinate services, and not to the agency that is providing that service.

We have an active advisory board made up of representatives from Alamance County Mental Health-Mental Retardation, Social Services, Public Health, Burlington City and Alamance County Schools, the Division of Vocational Rehabilitation, the Developmental Evaluation Center in Greensboro, and consumers, see p. 141).

I think one of the best ways to illustrate to you what we actually do and get away from the high-sounding theory is to describe two actual cases to you, and I would like to do that now and I would like to point out that these are not composites; they have had their names changed, however.

Sandy and Carole: during a periodic tracking, client's mother presented a number of problems. The case manager went to the home to meet with the mother and two daughters. Both girls have down's syndrome; Sandy is 19 and Carole is 17. Both girls attended the trainable mentally handicapped class in the city schools.

The mother has managed fairly well up until several months ago, when the father left the home and subsequently lost his job. He has not provided the family with any financial support, and the mother did not know which way to turn. Sandy has exhibited aggressive behavior toward her mother and sister over the years. When the father left, this became extreme and the mother was actually afraid of her own daughter.

The case manager in the initial meeting collected information about the two girls from the mother that she needed to know to work with them, and got all the proper permissions signed. The most immediate problem for all three in the family was probably the easiest problem to solve at that time—the lack of adequate financial resources. The mother does have a part-time job in a school cafeteria and, at the case manager's suggestion, the mother applied for and received supplemental security income and medicaid for the girls, and food stamps. She had all the information necessary to apply and there was not a great deal of problem there.

However, additional problem assessment with the mother and the daughters identified emotional and behavioral needs, and a written plan of action was agreed to by the case manager and the family was presented to the service planning team, and then the plan was put into action. The case manager arranged for counseling for the mother at the mental health center and for a behavior management plan for Sandy.

Both the mother and the therapist felt that Sandy should leave home for a while until the mother was able to get back on her feet. Additional problems identified and services sought were community respite care and after-school activity while the case manager was looking for openings in and making applications to a number of group homes for Sandy.

Putting the pieces together often requires a lot of flexibility and looking ahead. For example, an out-of-county group home opening did occur, but there could be no school transfer because of Sandy's age. So, the case manager looked into workshop possibilities, and Sandy was accepted into the group home and into the workshop in Caswell County, which adjoins our county. The case manager will check up on her periodically to be sure she is adjusting well.

There were numerous things that had to be done just to get to this point: detailed applications filled out; social histories done; psychologicals, medicals, health department forms; special assistance from social services; preliminary visits to the group homes; contacts with the school systems. The case manager did contact the local school system to be sure that Sandy would not be given a school-leaving certificate just in case things did not work out in Caswell County and she needed to come back home fairly quickly.

I am not trying to tell you everything that happened to this family, but I thought this might point out the kinds of problems that do arise for families and the things that they face. I would like to tell you that things are going well for them now. Sandy's aggressive behavior is diminishing; she is making a good adjustment at the group home and the workshop. The mother is coming along well too; last month, she phoned social services and told them to take her name off the food stamps list. They had helped her over a bad time, but now she is able to manage on her own, and she and Carole are living off of her income and Carole's SSI.

The case manager is looking for camperships, in the hope that the younger daughter, Carole, can go to resident camp for about 2 weeks this summer in order to give the mother some time to herself, after 16 years of caring for two developmentally disabled girls.

I would like to tell you about Catherine. Catherine is 23 years old and was referred to us for admission on paper only to the Regional Mental Retardation Center. The story was that her mother had taken her to North Carolina Memorial Hospital for kidney X-rays and for dental work, and they were unable to do that work there because of her extreme fear of the doctors and the hospital.

The doctor at North Carolina Memorial suggested that she apply to Murdoch Center, and then be transferred to Dorothea Dix Psychiatric Hospital for the medical workup to be done under anesthesia. She would never actually go to the Murdoch Center and would be discharged back home to Alamance County. Now, that seems like a long way around to get a medical workup done, and after doing some checking, the case manager found out that, indeed, Murdoch was reluctant to get involved. So, she took the following steps.

She encouraged the mother, on the client's behalf, to apply for medicaid, and that was approved. Then she was able to help the mother find a doctor and make an appointment with this doctor, who is local and has had good experience in working with developmentally disabled patients. He was willing to attempt to get the workup done locally.

The client may have to go into the hospital and, if so, they will have to pursue some limited guardianship. Once the medical problems are taken care of, then the case manager will work with the client and the family to get the client into community services.

But here is the part that I think is amazing, and it is very sad. This client has lived in Alamance County for 23 years and she has never been to school, to a workshop, or to anything, in a county that prides itself on its community services to developmentally disabled individuals. Yet, through this program, we were able to find her and get some help for her.

Our records were designed to meet the requirements of the developmental disabilities law for individualized habilitation plans. The entire client record becomes the IHP. As required by the law, the plan is signed both by the client—if 18 or over; if not, by the parent—and the case manager. This indicates that the service plan was developed jointly by the client and the case manager. All of this takes place within 30 days from the first contact with the family.

The plan that has been worked up by both the client and the case manager is presented to service planning team, made up of representatives from human service agencies in the county, and if they are in agreement, is signed by them. The team meets monthly, and in most instances the plan is approved. Sometimes services will need to be negotiated at this team meeting.

The service plan is put into action and the steps necessary to carry out the plan are written with events to occur and probable dates for occurence specified.

The case management system is backed up by a computerized management information system. It is management by exception in that clients who are doing well toward meeting their IHP goals are not called to the attention of the case manager. Those who are having difficulty or are due for periodic monitoring show up on a

printout that alerts the case manager to that individual's needs. Theory is that the computerized system will allow larger caseloads.

Our two case managers have caseloads of 69 and 70. We do not know what the maximum number a case manager can carry is, since we don't believe we've peaked yet. The system does not allow a case manager to overlook a client.

Developmentally disabled individuals needing case management services hear about our system from a number of sources; schools, agencies, institutions—such as hospitals and training schools—and word of mouth. We've even had four referrals from the public library. There are only two requirements to receive our service: The person must have a developmental disability as defined by the law, and must reside in Alamance County.

We have two kinds of clients—those who are referred to us for periodic tracking and those who have immediate problems. The example of Sandy and Carole—they had been referred for tracking only, but eventually problems did crop up for them. I think this backs up the thought that we have that our problems are lifelong and they are not just getting an answer to one specific thing and going on from there.

There is a need for what we call companion advocacy, and we are attempting to start such a program in a joint effort with our local association for retarded citizens. The case management system will screen and match up on a 1-to-1 basis clients—protegés—with volunteers—companions—recruited by the ARC who will spend no less than 2 hours a month being a friend, a willing listener, or perhaps a card partner. This is just in the beginning stages, but we are excited about it, and hope it will expand to other groups.

We believe that case management is an effective way to assure developmentally disabled individuals and their families access to the combination of services they need in order to attain their maximum potential.

Thank you for allowing me to tell you about our system, and thank you for your interest in handicapped people.

[The following was received for the record:]

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Senator WEICKER. Thank you very much, Julia, and I thank each member of the panel for speaking of your experiences and your expertise and helping this panel make its deliberations. Thank you very much.

The last panel is on Federal policy meeting the needs of persons with developmental disabilities, and recommendations for change. We have John McGee of Omaha, Nebr., a pscyhologist at the University of Nebraska Medical Center; and Ed Skarnulis of Frankfort, Ky., the director of the Division for Community Services for Mental Retardation, State of Kentucky.

I am delighted to have both of you here. As I indicated to you, the hearings had to terminate at 12:30, so you have got 3½ minutes for both of your presentations. But with the flexibility that at least sometimes can be a part of this institution, we would not in any way want to constrain your presentations, except within the bounds of what everybody else has been constrained with. We know it has been a great effort for you to get here, and let me assure you that we want to hear what is on your minds.

So, Dr. McGee, are you first up to bat here?

Dr. MCGEE. Yes.

Senator WEICKER. You go right ahead.

STATEMENT OF JOHN McGEE, PSYCHOLOGIST, UNIVERSITY OF NEBRASKA MEDICAL CENTER; AND ED SKARNULIS, DIRECTOR, DIVISION FOR COMMUNITY SERVICES FOR MENTAL RETARDATION, STATE OF KENTUCKY

Dr. MCGEE. Thank you very much, Senator, for having invited me to testify here; it is a pleasure.

I was going to make several points. I myself really do not understand all the political and economic things that are going on, but I do understand that there are tens of thousands still today, even with what we thought was a strong Developmental Disabilities Act; there are tens of thousands of mentally retarded citizens and other disabled citizens in institutions, abandoned at best, and subject to abuse at worst, whether it be your State, my State, or any of the other 48 States.

So, what I would like to do is illustrate the need for a stronger rather than a weaker Developmental Disabilities Act, and especially a stronger rather than what the Supreme Court just called the thin reed Bill of Rights Act in the Developmental Disabilities Act.

I would like to show, over about four minutes, 4 severely developmentally disabled persons, because I do not think they are yet citizens, who had been abandoned in horrible conditions up until very, very recently, in the last few weeks. I think these are the four people who would answer your very question, what about if States did not want to serve these people? These four people do receive the answer of, "Well, that is tough; you do not have rights."

The four persons you will see have been and will be abandoned if the act is not strengthened. These four represent the tens of thousands who are the last to be served, the least likely to be served in our Nation, and the most subject to abuse.

[A transcription follows of a videotape shown to the subcommittee:]

This is a 15-year-old young man who had spent the previous four years in a large state institution, virtually physically restrained most of the time. He would rebel and go into an outrage with any active treatment program.

Dr. McGEE. Even with the $6 billion that we spent last year, David has spent 4 years tied spread-eagled to a bed in a State institution.

[The transcription of the videotape continues as follows:]

This is a young man who had been expelled from public school for acting up when he was ten years old, and had virtually remained at home in his basement or in his bedroom for the last 14 years. He had very primitive behaviors and would refuse to participate in any developmental care.

Dr. McGEE. Even with Public Law 94-142, Steve spent from age 10 through 21 at home in his basement.

[The transcription of the videotape continues as follows:]

Paula is a 20-year-old young woman who had spent the early developmental years of her life in a state institution for the mentally retarded. She would not participate in any activities. She would refuse; she would run away and kick, yell, scream, and hit herself.

Valerie is a 20-year-old woman who had lived in a group home for the last four years and attended the local school district. Her severe behaviors have been brought under control, but during the previous summer, she regressed behaviorally and began banging her head 300 times an hour, refusing to participate in any program.

Dr. McGEE. This is one of her calmer moments.

[The transcription of the videotape continues as follows:]

We have seen four severely mentally retarded, emotionally disturbed adolescents and young adults who had been virtually denied services for a good part of their lives. The point finally comes where we have to make a decision as to whether or not Valerie, Paula, David and Steve should be in active developmental programs so that they can participate more fully in their human lives.

This work requires gentlemen, calmness, tolerance, warmth and control.

Dr. McGEE. I am going to advance it to anywhere from a couple of hours to a couple of weeks later, Senator. The point I would like to make in this is if Valerie, Paula, and David and Steve do not have a strong Development Disabilities Act and the kind of specificity that that Act gave relative to their rights, they will virtually be abandoned, whether it be in Connecticut or Nebraska, or any other State in the Nation.

They are tough to serve, but you will see in a second that they are quite capable of growth and development, given the kinds of specificity and power that we think the Developmental Disabilities Act has had. Also, you will see these same four people in their institutional setting, where many of them were hog-tied, tied to their beds, and in neglected situations, which cost the States that they were in anywhere from $35,000 a year to $70,000 a year. To get decent services in the least restrictive setting, and the right to treatment, is currently costing these four people half of what it costs to incarcerate them in institutions.

These are the same four people, anywhere from a couple of hours to a few weeks later.

[The transcription of the videotape continues as follows:]

Paula was placed in an intensive therapy program so that we could gain stimulus control over her behaviors.

Dr. McGEE. This was a community program. We got her out of the back ward of the institution she was in. Within a week, Paula would come in and would work. She now lives in a group home and

goes to a sheltered workshop. She is a significantly different human being because, through the DD Act, we had understood that she had the right to do this.

You can see her; this is just a few days later. She is not screaming; she is sitting there. She is still tough and will need lifelong support, but she can be part of the community.

[The transcription of the videotape continues as follows:]

After about two hours, Paula began to sit, follow instructions, and perform fairly complex tasks.

Dr. McGEE. This was her 2 hours later.

This is Steve about 6 weeks later, who had been in his basement for the previous 14 years and who was on the verge of going into an institution. Again, because in the State I am in we believe in the power of the Development Disabilities Act, and especially the Bill of Rights for these citizens, Steve is now living back in his home, but he goes out; he goes shopping, and he too goes to an industrial training center in the community that he lives in.

David, this profoundly retarded young man who was tied to his bed for the most part of 4 years, is back in his local school district, going to special school with a teacher's aide and living in a group home. He is assembling a 55-piece bicycle brake here, by the way.

[The transcription of the videotape continues as follows:]

David, like Paula and Steve, has been directed toward work. He will sit and allow the staff person to sit next to him without hitting.

All the young men and women that we have seen in this videotape came under instructional control in a matter of days. They required daily, day-long, intensive therapy. The professional had to master these techniques and be able to apply them in the right mix and in the right intensity with warmth and tolerance.

Dr. McGEE. Those are the four people. There are tens of thousands of such people in this Nation, and it is my testimony that I think the Development Disabilities Act, because of these tens of thousands of people, should be strengthened and not weakened.

[The prepared statement of Dr. McGee follows:]

Toward Family and Community Life for Developmentally Disabled Citizens

John J. McGee, Ph.D.
April 30, 1981

The purpose of my testimony is as follows:

A. To describe the needs of those citizens who currently reside in our nation's institutions, as well as to identify and clarify the myths which encompass this abandoned population.

B. To describe and demonstrate that the most severely involved developmentally disabled population can grow and develop in less restrictive alternatives - in their families and communities - and that, indeed, growth and development is likely to occur only in family and community-based alternatives.

C. To outline recommendations which would strengthen and ensure the family and community integration of all developmentally disabled children and adults throughout our nation.

Today's Institutions

The United States has witnessed a rapid and justifiable decrease in the number of developmentally disabled citizens in state institutions over the past two decades. While this reduction has occurred, billions of dollars have been invested in building up new institutions. The social policy thrust has been to deinstitutionalize those who could easily manage their lives in the community and simultaneously pour billions of federal and state dollars into building up the "new" institution. These dollars along with regulations and accreditation standards were to have made the difference between institutions being places of neglect and abuse versus places of loving care and human development. This simply has not happened.

For example, in a recent evaluation of Joint Commission for the Accreditation of Hospitals survey data from forty-eight state mental retardation facility surveys performed in twenty-one states, thirty-five facilities failed this critical minimal test of treatment quality (Braddock, 1977). Those which were not accredited failed primarily for the following reasons:

1. The excessive use of chemical restraint and physical seclusion;
2. The impersonal nature of the physical environment;
3. Fxcessive crowding of residents in living spaces;
4. The failure to provide comprehensive, interdisciplinary initial and periodic evaluation, program planning, follow-up in relation to educational needs or rehabilitative needs, as well as a general lack of developmental services;
5. The lack of the use of direct care personnel in training residents in self-help skills; and
6. The failure to employ sufficient numbers of qualified personnel in direct care service, dentistry, education, nursing, physical and occupational therapy, psychology, recreation, social services, speech pathology and audiology, and vocational training.

These deficiencies are not the result of minor mismanagement which can be eliminated by pouring in more money. Rights must be clearly established. Newer buildings and more manpower will not eradicate the elements which make up the very nature of an institution: isolation, removal from ongoing public and professional scrutiny, segregation, depersonalization, and in the worst cases, direct abuse of the residents.

Those Who Currently Reside in Today's Institutions

Nor should these problems be blamed on the developmentally disabled. Unfortunately, some professionals believe that the remaining 135,000 institutionalized, mentally retarded citizens are "decerebrates" who merit only what they term "enriched environments" (Ellis, et al., 1978).

This report incorrectly stated that a substantial number of institutionalized persons have such a low potential for growth that training programs seem inappropriate and that those residents should be assigned to enriched daily living programs. This unfortunate view is clearly contradicted by a study of the basic needs of Nebraska's institutionalized mentally retarded population (Horacek v. Exon, 1978). It is important that today's professionals, parents and policy makers understand who resides in today's institutions. The Nebraska data strongly indicates that the 873 mentally retarded persons in its state institutions are not persons who should be doomed to life-long custodial care.

The Nebraska study showed that of the state's 873 institutionalized mentally retarded persons only 74 had major medical or major behavioral needs. A person with major to moderate medical support needs was defined as requiring immediate medical back-up support. A person with major behavioral needs was defined as generally requiring a very structured, intensive, behavior change-oriented environment with a 1:1 staff-to-client ratio. The large majority of institutionalized persons, however, would present no major problems relative to their placement in community-based alternatives given adequate resources and support. Indeed, Nebraska's community-based programs currently serve a population as complex as those found in the institutions (ENCOR, 1979).

Almost two-thirds of these 873 persons come from the urban areas of Nebraska, thereby dispelling a corollary myth that the large majority of those with the

most special needs were from rural areas. This assumption had led to the incorrect conclusion that large numbers of retarded persons could not be served in communities which had few resources. In Nebraska, the institutionalized population is proportionately distributed across the state. There is no validity to the repeated argument that the institutionalized population is skewed toward the rural areas of this state, and perhaps to other states.

The study indicated that over 500 of the 873 institutionalized persons had their major self-care needs. Nebraska's institutions house those who need help in toileting, bathing, dressing, feeding, etc. Yet, the large majority of the people could move about; 587 of the 873 persons had minimal mobility needs (i.e., they could walk without any assistance). The large majority had appropriate behaviors: 517 persons required little or no intervention relative to their interpersonal interactions. The large majority were not medically fragile: 597 of the 873 persons had no more than routine medical needs.

Indeed, the medically fragile, mentally retarded population is considered to be one group which demands institutional care the most. However, a further refutation of the Partlow argument can be made based on a study of Nebraska's institutional and community-based mentally retarded population. In this study Touche Ross and Company (1980) made the following conclusions:

1. In the opinion of the Nebraska institution's medical staff, only eight institutionalized mentally retarded persons required medical services not typically provided in Nebraska's community-based mental retardation programs.

2. All other institutionalized persons with special medical needs could be adequately and appropriately served in community-based programs given: (a) the proximity of appropriate medical services, (b) special training for residential and day program staff, (c) barrier-free facilities and (d) additional staffing to assist in self-care, ambulation and positioning.

It is the areas of behavioral and developmental needs which can generally be surprising and favorably dealt with through specific, individualized programming

contrary to the Partlow Committee's posture. Experience has shown that people with similar needs in community settings typically attain many of these skills after consistent exposure to developmental programming. In fact, the aforementioned Touche Ross report states that the amount of direct care (developmental) services in community programs in Nebraska for the most severely involved is approximately 42 hours per week as opposed to the institutions 21 to 32 hours per week. Thus, the highest need mentally retarded persons receive more developmental services in community programs than in the institution. Even those who do not attain all of these skills can still be supported in community settings in a humane and dignified manner. Confirmation of this goal is the fact that Nebraska has virtually eliminated new admissions of retarded persons into institutions. Today there are only ten children less than six years of age, and only 240 school-age children in Nebraska's institutions. Of these, over two-thirds are in their late adolescent years. Early identification, early intervention, in-home supports, parent training, etc., have eliminated the need for institutionalization in all but the rarest instances. In fact, one of the most powerful force in deinstitutionalization in Nebraska has been the virtual halt of new admissions to the institution.

Those who are institutionalized in Nebraska are the middle-aged mentally retarded persons who had no other alternatives in previous decades. They were placed there when there were no community alternatives, when rights had not yet been articulated and when families had no alternatives. These alternatives exist today in Nebraska communities and most other states. Where they do not exist, they should and could be developed. Thus, placement into less restrictive alternatives is possible and should be mandatory.

The fact of the matter is that the institutional population is a complex and challenging population, but it is not the type described by pro-institutional proponents. The large majority are neither medically fragile, nor behaviorally

violent. The last two decades of applied research clearly demonstrates that all mentally retarded persons are capable of growth and development. All are sentient human beings who can learn (Berkson and Landesman-Dwyer, 1977). This includes all those who reside in today's institutions.

The Family and Community as the Least Restrictive Alternative

"We cannot make the assumption that by dumping these individuals out of the institutions, the community will somehow assume its responsibility and will begin to treat them like human beings... Communities have herded 'deinstitutionalized' persons into a wide variety of equally restrictive or more restricted environments..." (Leland, 1981). There is much ignorance both on the side of pro-institutional advocates and pro-community advocates about the nature of community-based alternatives. At times the act of deinstitutionalization can be equated with dumping, that is, the act of blindly moving persons out of instituitons into any place which can house them in the community regardless of individual needs. Dumping often occurs into such places as nursing homes, board and room homes, hotels for transients, etc. Dumping makes a sham out of rights. It is often reinforced by contradictory federal policies.

Dumping is deinstitutionalization only in the sense that it reduces the number of people in state institutions. However, it is clearly not the placement of mentally retarded persons into less restrictive environments which meet their basic human and developmental needs. True deinstitutionalization is not the mere reduction of the number of persons residing in institutions, rather it is the individualized placement of each mentally retarded person into a community-based service delivery system which ensures the physical, spiritual and developmental well-being of the mentally retarded person across his/her lifespan. It is the guarantee of an array of residential, educational, vocational and leisure time services based on each mentally retarded person's needs.

Alternatives to Institutions for Severely Involved Persons

My data and experiences indicate that for those mentally retarded and other developmentally disabled persons, persons with more complex behavioral, medical and developmental needs the "new" institution is unwarranted. Deinstitutionalization is a function of the development of adequate and appropriate community-based services. This does not mean that all institutionlized persons can immediately move directly into their communities. Adequate and appropriate alternatives still must be developed in most communities across the nation. Community-based alternatives must be able to ensure mentally retarded persons and their families that there will be:

1. A variety of community-based less restrictive options which utilize modern treatment and programmatic techniques in small dispersed residential, educational, vocational and leisure-time services;
2. Maximum parental input while still ensuring individual client rights;
3. On-going internal and external monitoring of the quality of services;
4. A realistic cost per person for services, and assurance that program financing will be ensured across time; and
5. Prudent risk for all mentally retarded citizens as they live, work and play in communities, while at the same time safeguarding each person as much as necessary.

Community programs can adequately, appropriately and developmentally serve even the most severely involved mentally retarded children and adults. The ENCOR (Nebraska) and Macomb-Oakland (Michigan) programs demonstrate this fact (Menolascino, 1977; Biklen, 1979). Services for the most severely involved clients can be characterized in the following manner:

1. They are concrete, comprehensive, replicable, developmentally-oriented programs;

2. They are ensured across the person's lifespan based on the degree and intensity of services required by each individual;

3. They are small, no more than six to eight persons being housed in any given setting;

4. The various programs and services are dispersed throughout the community and state in a well-managed service delivery system;

5. Manpower resources are derived and trained from the local community with adequate medical and psychiatric back-up personnel.

Barriers to Movement

If the vast majority of those who are housed in institutions are not there due to their personal needs, why are they there? There are several barriers which impede the movement of people out of institutions and which contribute to their placement into institutions.

1. There are several persistent inter-related misconceptions about who is currently institutionalized. These misconceptions have been examined above. Their effect, if allowed to spread, would be to undermine efforts to create community-based alternatives and to make institutionalization appear as an accepted course of action.

2. There are also related misconceptions about who can be served in community programs. Quality community programs can serve nearly anyone who is currently institutionlized, given re-distribution of money, manpower, and management systems and, more importantly, a rebirth of the human and legal rights of all citizens.

3. There are several misconceptions about what community-based alternatives to institutions are. They are not mini-institutions. They cannot be dumping grounds. They must be small, dispersed and developmentally-oriented environments which ensure adequate and appropriate services across each person's lifespan.

4. Finally, there is a myriad of federal and state social policies and funding mechanisms which promote incentives to institutionalization, transinstitutionlization and dumping while at the same time providing disincentives to the development of community and family support.

The movement of mentally retarded citizens from institutional environments to community-based alternatives requires the movement of the resources currently

allocated to institutions. In other words, it costs money to support persons in their community and in their family. The hundreds of millions of dollars that are expended in today's "new" institutions must be redistributed as the people move into community and family life. This financial reality, the need for money to follow the client from the institution to the community was underscored as early as 1970 by the President's Committee on Mental Retardation (Cook, 1970). As the retarded and other disabled persons are integrated into community systems of care, so too must the financial resources be redistributed. Community-based programs have demonstrated themselves to be cost-effective when compared to institutional costs. For example, in 1980-81 Nebraska's community-based programs, serving a similar population, spend slightly over $12,000 per year per person as compared to over $30,000 per year per person in Nebraska's state institutions for the mentally retarded (Horacek v. Exon, 1978). More importantly, our professional societal postures toward retarded persons must be unified so that the catch 22 of today's social policies and financial outlays can be resolved in a positive fashion. Society cannot ensure some of its retarded citizens community integration while millions of dollars continue to be spent to institutionalize their mirror images in "enriched" institutions.

Conclusion

The overwhelming majority of mentally retarded persons who currently reside in our nation's institutions are not there because of some exotic need related to their disability. All retarded persons are capable of growth and development. The professional posture that some retarded citizens are "sub-trainable" and hence need to reside in "enriched" institutional settings for the rest of their lives is an archaic one contradicted by the major

ideological and programmatic breakthroughs of the last two decades (Menolascino, 1977). Currently institutionalized mentally retarded persons are there because of archaic professional views which persistently support social policies which are designed to maintain institutions regardless of the demonstrable needs and potential of the mentally retarded persons who reside therein. The "new" institution has taken on a new language, a new look and new management neologisms; yet it is still a system which generally dehumanizes and depersonalizes its residents in the same procrustean bed. Yet, we should take heart that communities across the country are serving mentally retarded persons of all level of needs in spite of the array of regressive professional postures and social policies noted above. Parents and professions, as well as the mentally retarded themselves, are pushing for further public and professional education to help rapidly support emerging national policies which are based on the normalization principle, the right to treatment, the right to the least restrictive setting and the developmental aspects of community-based service systems which enhance the person, the family and the community. These emerging social policies must stress for families and retarded citizens themselves a continuum of service choices. These choices, contrary to "enriched environment" proponents, must accept all retarded persons as developmental beings and must utilize state of the art techniques to ensure maximum growth and development in America's family and community life.

Based on the above, I specifically recommend the following:

1. The Bill of Rights for the Developmentally Disabled should be strengthened so that all developmentally disabled persons are ensured the right to community and family services, the right to treatment based on their individualized needs, the right to due process, the right to education and the right to be free from harm.

2. The Developmental Disabilities Act remain separate and distinct from other legislation because - once subsumed - these citizens tend to be the last to be served, the least likely to be served, and the most subject to abuse.

3. The Act should direct the power of this nation's University Affiliated Facilities away from the support of institutions and toward the development of manpower training for parents, paraprofessionals and professionals in communities across this nation.

4. The Act should continue to focus its funding toward the demonstration of family-centered and community-based models for the most severely involved disabled citizens.

In summary, I ask not for more money, but rather for a firm national voice that says - all disabled persons in America are citizens of our land, all have the right to remain in their families and communities.

Senator WEICKER. That is very effective testimony, Dr. McGee. I apologize to everybody; I should have asked you all to come this way so that you could have seen it before the showing got started. But I am sure that after the hearings end here, Dr. McGee will be glad to show it to anybody who would like to see it.

Thank you very much; thank you very much.

Ed Skarnulis, director for the Division of Community Services for Mental Retardation, State of Kentucky. Mr. Skarnulis?

Mr. SKARNULIS. Thank you very much, and thank you, John.

In Kentucky, we are trying to establish a humane system of community alternatives to the traditional institutional model for people with developmental disabilities. By way of an apology, while I use the terms "mental retardation" and "development disabilities" interchangeably, it is not intended to be a failure to respect the difference between the two terms. To my colleagues and friends in the field of developmental disabilities who have other developmental needs, just pardon my slip; it comes from 15 years of working in the field of mental retardation.

Also, my job is to primarily focus on that group of people—a significant group of people; 1 out of every 10 households has someone with mental retardation in their household.

The primary concern we have in Kentucky, and I hope the relationship to developmental disability is clear, is that the existing funding streams and the existing mechanisms for provision of adequate community services for all citizens with developmental disabilities are spotty at best, and at times almost impossible. I will give some examples of that.

Much of that funding stream difficulty is related to some perceptions and some assumptions that we have about this group of people—some assumptions that I suspect many people fall err to when they see the first part of John's videotape, in which they hear noises and see behaviors that conjure up some very negative images of that group of people. Hopefully, those images are changed at the end of the videotape, when we see that these are, in fact, citizens and that they can grow and develop.

In Kentucky at the present time, our funding streams are pretty much dictated by many of the Federal rules and regulations, and those Federal rules and regulations say that 70 percent of our $339 million that is available for people with developmental disabilities and with other kinds of needs, such as the elderly, must go into institutional-type settings.

The current administration, under Gov. John Y. Brown and Secretary of Human Resources, Dr. Grady Stumbell, very fervently supports development of humane community alternatives. But they frequently find themselves in the paradox of not being able to provide those alternatives because of the dictates of the funding streams.

We have literally in our State, and I think in others as well, created an industry, and I am thinking particularly of the health industry, which is designed to respond to those kinds of mandates and which is designed to chase the funding streams. We have, in Kentucky, one chance for the brass ring. Our Governor cannot be reelected under our laws, so those of us who are political appointees in this administration have 3 to 4 years, during which time we

can try to put in place a set of community alternatives that are humane. If we do not make it during that 3 to 4 years, then we have no assurance that the next executive branch will want to carry out those approaches.

So, we are very intensely concerned, as you might imagine, with what is going to happen during the current debates here in Washington on how funding will be provided to the States.

I think it strains the credulity of most people in this country to believe that the system we have been operating under, the institutional system, has in fact some serious defects in it. Some of those, John has alluded to. Jerry Provencal, who wryly refers to himself as a superintendent, has alluded to others The fact is that large custodial environments for this group of people—people with mental retardation—has been challenged and found wanting almost since its inception, since 1848, when Edward Sagan and Samuel Gridley Howe first started an institution for mentally retarded people.

Twenty-six years later, after Howe had had some experience with this field, he had this to say in his report of the superintendent to the trustees of the Massachusetts School for Idiotic Children, and pardon the terminology, but that is a function of time:

> Now, the danger of misdirection in this pious and benevolent work is that two false principles may be incorporated with the projected institutions which will be as rotten piles in the foundation and make the future establishments deplorably defective and mischievous. These are: first, close congregation and, second, lifelong association of a large number of idiots, whereas the true, sound principles are separation of idiots from each other and diffusion among the normal population.
>
> For these and other reasons, it is unwise to organize establishments for teaching and training of idiotic children upon such principles as will tend to make them become asylums for life. Even idiots have rights which should be carefully considered.
>
> At any rate, let us try for something which shall not imply segregating the wards and our classes, removing them from our sight and knowledge, ridding ourselves of our responsibility as neighbors, and leaving the wards closely packed in establishments where the spirit of pauperism is surely engendered and the morbid peculiarities of each are intensified by constant and close association of others of this class.

I think those same words could be repeated today and, in effect, have been repeated by Dr. McGee.

For over a decade, we have been trying to establish community residential alternatives in this country, and it has been an uphill battle. For those of us who have been on the cutting edge of that movement, many of us are scarred and bloodied. One of the few programs which has given us hope and which has been a beacon in this whole effort has been the developmental disabilities program.

As pitiful as it is in terms of funding levels, nevertheless it said some things, particularly in its bill of rights, which are essential and which are germane to the kinds of things that we are into. For example, in the bill of rights it alludes to the less restrictive alternative and to the right of the person to stay in his own home, if that can possible be done.

There is no question, I think, in most people's minds that a "support not supplant" the natural home approach is not only more economical and not only more humane, but also makes sense in terms of education and training. There are some people who have to leave their homes, but I think we need to demonstrate more clearly than we have in the past that we have taken every measure necessary to prevent that kind of separation.

There are a number of myths, such as that developmentally disabled people should be with their own kind and that they are happier with their own kind. That frequently ignores the definition of what "one's own kind" really means. But even if we were to accept that on some sort of moralistic basis, I think the fact remains that the experiences we are gaining in the field indicate to us clearly that people with mental retardation learn by imitation, and the more severe their handicap, the more they tend to depend on imitation of those around them as their method of learning. If we surround them with people whose behavior is aberrant and whose behavior is perceived to be deviant by the rest of society, it is hard for us to expect anything but that same kind of aberrant or deviantly perceived behavior.

For the sake of time, I am going to sum up.

Senator WEICKER. Your statement will be included in its entirety in the record.

Mr. SKARNULIS. OK, fine.

I have to confess that I think I and a lot of other professionals have a strong motive for wanting to move toward a "support not supplant" the natural home philosopy. In some ways, it is kind of a personal motive.

We attend international congregations and, frequently, at those meetings we find ourselves surrounded by people who represent the so-called underdeveloped nations of the world and the so-called Third World nations. Many of our colleagues from those countries sit in awe as they listen to those of us from the Western nations talk about the need to deinstitutionalize and the need to get rid of some of the large congregate care institutions we have.

They are appalled, because as most of them tell us, they could not afford that, if they wanted to. So, it is an embarrassment, to be perfectly blunt about it, to go to those meetings and to have those colleagues actually be far ahead of us, when we have the resources to be doing so much more than we can be doing in this area.

It is reminiscent of what I think is probably the best statement on this issue that has been made, and that is by the peacemaker, Ghandi, who when asked by some reporters what he thought of western civilization is reported to have said, "I think it would be a good idea."

Senator WEICKER. Thank you very much.

[The prepared statement of Mr. Skarnulis and additional material supplied for the record follow:]

LEARNING FROM EXPERIENCE:

CONGREGATE RESIDENCES IN THE UNITED STATES [1]

By: EDWARD R. SKARNULIS, Ph.D.
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Introduction

In July, 1979 I received a thoughtful position paper (Center on Human Policy, 1979) which argued that the time had come for people to publicly support the deinstitutionalization movement in the United States. The authors chose not to base their arguments on clinical or scientific grounds alone, but rather on moral, ethical, and legal grounds.

I endorsed their humanistic and legal arguments which favor smaller, more normal community residences. Nevertheless, a strong clinical or scientific basis for such a position is also available to us. In this paper I propose to share with you our experiences and outline some of the social science research which exists. While various studies cited here are of a correlational research design, it is hoped that the patterns and weight of evidence will lend support to those conclusions reached by the Center on Human Policy.

Further, it is hoped that a sharing of experience through this document will be helpful to the designers of future residential services in communities within and beyond the United States.

History of Deinstitutionalization

For over one hundred years it has been common practice in the United States to place mentally retarded children and adults into residences outside their own homes. Initially such placements were intended for the purpose of training the mentally retarded persons for eventual return as productive members of their local communities. The residences were essentially "boarding schools," usually located in urban areas, small in size, and designed for limited terms of residence (Gollay, et. al., 1978; Wolfensberger, 1969). Gradually, however, the purpose shifted from an educational one, where terms of residence were limited, to a custodial function, where lifelong residence was assumed (Skarnulis, 1974). Facilities grew in size until their populations numbered several thousand children and adults, and such institutions were increasingly constructed in remote areas, away from the mainstream of community life.

In recent years services in communities have been expanding, the populations of large state-owned institutions have declined, and in-home support services for families have often eliminated the need to place handicapped members outside the home. This new trend, deinstitutionalization, has resulted in a national reduction of institutionalized mentally retarded citizens from 181,035 in 1971 to 153,584 in 1976 (Gollay, et. al., 1978), as well as a significant reduction in institution admissions and readmissions (Krause, 1976).

[1] Presented March 20, 1980 to the Michigan Chapter of the American Association on Mental Deficiency, Traverse City, Michigan. Also delivered (in revised form) to the "International Congress of Parents and Families of Persons with Mental Handicap," Barcelona, Spain, June 14, 1980.

There are several reasons why the deinstitutionalization movement occurred. Beginning in the 1930's parents of mentally retarded persons banded together to form local associations, and in 1950 they formed their own national organization, now called the National Association for Retarded Citizens (NARC). Their interest centered on: (1) improving educational opportunities and living conditions in institutions; and (2) developing alternative services in communities for those families who chose to keep their children in the natural home. In 1963 the parents were given strong support for their cause by President John F. Kennedy, who publicly acknowledged that his sister was mentally retarded, decried the neglect of this significant minority and called for national support of the goals of the parents. Abuse and neglect of mentally retarded persons in institutions were exposed by the press and professional employees working in such settings (e.g., Blatt and Kaplan, 1966), and the visible decline resulting in movement away from an educational purpose toward warehousing of residents became a source of public shame. Enabling legislation was passed at all levels of government to develop community services and improve institutions through population reduction.

While parents, professionals, and interested citizens denounced the inhumane conditions existing in institutions there was no serious concern expressed in any quarter that institutions might be systemically defective. The generally held view was that, given adequate material resources and skilled personnel with proper attitudes, institutions could effectively carry out the tasks of education and treatment with an implied goal of eventual return of the resident to the community.

However, in the mid 1960's a growing number of people began to question whether the service delivery system itself, the institution, was necessary or even desirable. Was it possible that what was begun 130 years earlier was proving to be, not only not helpful, but harmful? Had we created a breeding ground for intellectual retardation rather than an environment designed to ameliorate it?

Had we ignored the admonitions of one of the institution's early champions? In 1866, Samuel Gridley Howe warned of its weaknesses at the laying of the cornerstone of the Batavia, New York, State Institution for the Blind:

> . . . Society, moved by pity for some special form of suffering, hastens to build up establishments which sometimes increase the very evil which it wished to lessen. . . . Our people have rather a passion for public institutions, and when their attention is attracted to any suffering class, they make haste to organize one for its benefit . . . .
>
> All great establishments in the nature of boarding schools, where the sexes must be separated; where there must be boarding in common, and sleeping in congregate dormitories; where there must be routine and formality, and restraint, and repression of individuality, where the chores

> and refining influences of the true family relation cannot be had, all such institutions are unnatural, undesirable, and very liable to abuse. We should have as few of them as possible, and those few should be kept as small as possible. The human family is the unit of society. (U.S. Department of Health Education and Welfare, 1976).

In the beginning, institution construction was an outgrowth of a demand for social reform, for improved conditions, led by sincere humanists like Dorothea Dix and Samuel Gridley Howe. The more recent institution reform movement has been motivated by the same concern about inhumane conditions observed a century earlier by Dix and Howe in communities, conditions the institution was intended to cure. The President's Committee on Mental Retardation reflected the emotional mood at the beginning of the deinstitutionalization movement in its review of the history of mental retardation, Mental Retardation: Past and Present (1976):

> As the fires of World War II burned out, a smoldering volcano of outraged parenthood erupted, and the mountainsides of public opinion moved . . . But the world had been deeply indoctrinated with an image which made a mentally limited child a product and a progenitor of evil heredity and social degeneracy, a subhuman or nonhuman contaminant of the human race. This demonic image had persisted in popular thought, in statutory codes, in the regulations of educational systems, in the practices of courts, in the judgement of most of the professionals and in the dehumanizing environments of mass-care institutions..

Reactionary Movement

Recently, however, numerous authors have called for empirical research to support continued population reduction. They argue that humanitarian appeals are not enough. Gollay, et. al. (1978), says that the general atmosphere surrounding the movement is one of "conflicting pressures and strong sentiments", that it is a "social phenomenon", that it is "difficult to generalize" about studies on institution reform. Vitello (1977) goes even further and says that research studies on the subject ". . . lack a control group, (and) any conclusions drawn can only be impressionistic and imprecise at best". Bachrach (1978) says that this is a protest movement, and has confused the "locus of care and quality of care."

There have been attempts made to slow down or stop the population reduction. For example, in 1974 "deinstitutionalization" was defined so that it did not simply mean moving people out of institutions into programs of comparable quality in communities; instead the National Association of Superintendents of Public Institutions said that deinstitutionalization definitions should include "return to the community of all residents who have been prepared through programs of habilitation and training to function adequately in appropriate local settings (Thurlow, et. al., 1978)."

The assumptions injected into this new definition are interesting. First, it is assumed that the reason for placement is solely a medical, educational, or behavioral need within the mentally retarded person. There have been, however, many other reasons for placement into institutions including family poverty; emotional/physical illness in parents; a shortage of schools, recreation, jobs, or other community services; temporary disruption of the family unit due to death, illness, or divorce. All of the training or treatment in the world will not enable a child or adult with mental retardation to return to the community until the true circumstances causing removal from the home have been addressed.

The assumption is that staff in an institution many miles distant from the home can determine what amount and kind of training is "adequate" to permit return to the home without any knowledge of the unique conditions which exist in a home or community, or awareness of all resources available to meet needs. Each day citizens who cannot read invent creative ways to survive in literate societies; blind and deaf citizens adapt to their surroundings in equally unique ways. Such adaptation is possible only through immersion in community life.

This new definition of deinstitutionalization was subsequently inculcated into a government funding program, Title XIX, which has been largely restricted in most states to improving institutional settings in order to "prepare people" for eventual return to the community. Such casuistry was not limited to deinstitutionalization but was applied as well to concepts like normalization. Some people have derided the term, claiming it meant "to make normal," to which Gunnar Dybwad (1977), our current President of the International League of Societies for the Mentally Handicapped, has eloquently replied:

> Neither Bank - Mikkelsen of Denmark who developed it in 1959, nor Bengt Nirje of Sweden who first formulated it in English in 1969, ever saw this principle as aiming at "normalizing people," a thought abhorrent to both of them. Rather, they were disquieted by the many ways in which the daily life of mentally retarded persons, particularly those in residential institutions, had been <u>de-normalized</u> and <u>de-humanized</u>.

A. Z. Soforenko, Superintendent of the state of Ohio's largest institution (2000 residents), has engaged in sophistry of the first order, in a speech entitled "The Role of the Large Institution in the Future of Residential Services" (1978), in which he argues that Normalization means subjecting persons with mental retardation ". . . to the same torturous life we face . . . ." His sarcasm is not lost when he says, "Why shouldn't everyone suffer as we do . . . ?" Again, responding to such arguments Dybwad (1977) has said that, "The Normalization Principle does not represent a way which is simplistic by making everybody look or act the same way. That is regimentation. Normalization proceeds from the basic fact that <u>it is normal to be different</u>. . . ."

Another backlash against the deinstitutionalization movement occurred more recently when a group of ten experts in mental retardation participated in

filing a "motion for modification" in a famous U.S. court case, Wyatt vs. Hardin (originally Wyatt vs. Stickney). The Wyatt vs. Hardin case required that persons with mental retardation must be served in the least restrictive environment possible and must receive appropriate treatment or training while there. The ten experts took issue with the concept of deinstitutionalization as it had been set forth in Wyatt, and held that only a small number of the institutionalized residents in that facility could reasonably be expected to adjust to community living. Further, they concluded that for a substantial number of the institutionalized residents, their potential for behavioral improvement was so low as to render training programs inappropriate and possibly punishing or demeaning. The experts called instead for "enriched" institutional care (Center on Human Policy, 1979).

Research on Congregate Living

In the United States we have tended to argue for humane community programs on the grounds that such programs are morally justifiable or legally defensible. News media exposes and legal actions have focused on the need for remediation of deplorable living conditions. However, as noted earlier, a number of individuals and groups are demanding that community programs justify their existance. Small, normative living such as individual foster homes, respite care, or family support is characterized as an interloper service system, while the institution is characterized as a demonstrably effective traditional service system, yet a review of literature in the field challenges that assumption.

Studies in the field of corrections, mental health and mental retardation, generally concur that the longer the stay in residence, the greater the likelihood the person will not be returned to the natural home. In the study of 133 psychiatric patients released from an institution between December, 1973 and December, 1974, Jan (1977) found that the greater the frequency of visits by patients to relative's homes, the shorter their stay in the hospitals. Unless we view residential services as purely custodial, it seems logical that we should keep people as close as possible to their homes in order to encourage family interest and visit frequency.

A substantial body of knowledge has been developed on imitation by Bandura (1977), Flanders (1968), and others. Cullinan, et. al. (1975) suggested that the field of special education should include research into the implications of such knowledge. The same could be said for the field of residential services. Cullinan said that: "Imitative learning is also referred to variously as modeling, vicarious learning, identificatory learning and learning through observation. In contrast to the many applications of operant-learning principles, however, the potentially useful findings on imitative learning have not been widely employed in special education. Further, they have received undeservedly little emphasis in many expositions of behavior change techniques. It is often pointed out that reinforcement principles function in the classroom whether they are systematically used or not." That our environment influences how we learn and how we behave is well established in social science

literature. Our senses of sight, touch, hearing, smell, feeling, and taste are bombarded constantly by an ever-changing myriad of stimuli from the world around us. These stimuli surround us while we learn and grow.

Since we learn through imitation of the behavior of others, living in normal homes with increased opportunities for imitation of normal models should increase the normalcy of the behavior of persons with retardation. By the same token, persons living in houses with few normal models would be deprived of opportunities for appropriate imitative learning. Those living with large numbers of persons with mental retardation would be imitating inappropriate behavior and would be less likely, therefore, to behave in an acceptable way in normative environments. As Bandura and Walters (1963) have noted, "The efficacy of normative models in shaping and controlling behavior has been abundantly documented in the research of social psychologists, but few systematic attempts have been made to relate the concepts and principles guiding experimental social psychology to those of current learning theory." Peterson, Peterson and Scriven (1977) studied imitation among non-handicapped and handicapped preschoolers. They concluded that if handicapped children and non-handicapped children are placed together both the handicapped children and the non-handicapped children will imitate the behavior of other non-handicapped children. They studied 29 children, 14 of whom showed serious delays in development according to the Denver Developmental Screening Test. Using both normal and handicapped children in modeling situations, they concluded that both groups were more likely to imitate non-handicapped peers rather than handicapped ones. This supports the hypothesis, therefore, that we need to take a harder look at the importance of placing mentally retarded children into integrated settings, giving them more opportunities to imitate normal behaviors rather than abnormal ones. For example, early integration in nurseries. pre-schools, or day care programs has been very successful.* The Peterson, Peterson, and Scriven study also raises serious questions about the common belief that the presence of a handicapped child in a home or school will cause the non-handicaped children (siblings or classmates) to suffer by imitating an inappropriate model.

It is not unusual for the average citizen to confuse cause and effect (or victim and crime) when observing aberrant behavior among institutionalized persons. Withdrawal, violent behavior, incoherent sounds or meaningless gestures are offered as justification for continued segregation of severely retarded persons away from the rest of the human family. Such behaviors might more accurately be viewed as evidence of the need for even greater assimilation of persons with a limited repertoire of learning abilities into normal society. A curious paradox in this regard is a trend in the United States to place more capable persons out of institutions first, while leaving persons with severe or profound levels of retardation in institutions. The latter group is least able to cope with abnormal living environments, to avoid learning inappropriate

* For an excellent slide/audio film on this subject, see the Eastern Nebraska Community Office of Retardation's "Why Be Friends." A documentary, it shows how normal and severely handicapped children mutually benefitted from a pre-school experience. (ENCOR, 885 So. 72 St., Omaha, Nebraska, U.S.A.).

behaviors in such environments. A more logical population reduction scheme might have been to leave the more capable persons (moderate and mild levels) in the pathological environment until those less capable and more vulnerable had been placed.

Another example of this "more sinned against than sinning" paradox is offered. Our television and movie industries regularly produce horror films which portray persons with normal intelligence helplessly trapped in institutions for persons who are emotionally disturbed or mentally retarded. If it is a nightmare for a normal, healthy human being to be victimized thusly, is it not equally frightening for the other wounded, defenseless human beings who permanently inhabit such settings?

A paper produced recently by the Center on Human Policy at Syracuse University (1979), lists other concerns raised by research on institution models:

> . . . We know that interaction between institutionalized clients and other people, either other clients or treatment staff, drops substantially in the insitutional environment (Goffman, 1961; Provence and Lipton, 1962; and Giles, 1971). We know that institutions are more often than not unstimulating environments (Flint, 1966). . . . We know that institutionalized children frequently become apathetic and isolated (Hobbs, 1975) or overly anxious to gain recognition and attention (Yarrow, 1962). Within just a few hours of entering an institution, residents tend to become dramatically less normal, both in appearance and in interaction with others (Holland, 1971). We know that institutional life can promote perseveration behavior. We know that the people who seem to benefit most from institutions are those who came from what clinicians have regarded as the worst home situations (Zigler and Balla, 1976). In other words, the institution was a relatively positive experience only in relation to more miserable pre-institutional experiences. And we know that people who have been institutionalized for long periods of time become more imitative and more conforming (Zigler and Balla, 1977). We know too that institutions can teach infants to be non-ambulatory (DeGrandpre, 1974). Ironically, some critics of total deinstitutionalization have themselves reported an inverse relationship between institutional size and quality of care. Institutions with smaller living units are superior to those with larger ones and most importantly, group home residences of 10 residents or less, in the community, tend to be more resident oriented (Zigler and Balla, 1976; and McCormick, Balla and Zigler, 1975). Further, a comparison of severely handicapped children in institutional and small community settings provides substantial evidence of greater skills development among clients in the small community settings (Kushlick, 1976; Tizard, 1969).

(7)

Another study of significance is the classic longitudinal study of the effects of an institutional environment on mentally retarded persons done by Skeels and Skodak (1966) at Glenwood State Hospital-School in Glenwood, Iowa. What is significant about the study is that it spans four decades of solidly documented research. The study followed the progress of 25 institutionalized children. Thirteen of those children were in an experimental group and the other 12, of course, were in the control or contrast group. Both the experimental and contrast group children had been diagnosed as being mentally retarded. During the study, 11 children of the experimental group were placed into adoptive homes. The contrast group, on the other hand, was allowed to stay in the institutional environment with no intervention by the researchers. While the contrast group tested significantly higher in intelligence than did the experimental group at the beginning of the study, at the end of 2 years, the experimental group had made an average gain of 28.5 I.Q. points and the contrast group showed a loss of 26.2 I.Q. points. In the adulthood follow-up study, published in 1966, the experimental group continued to show significantly greater achievement in education, income and occupational level, than did the contrast group.

While it's important to focus on the environment's effect on the learning ability, and personal growth and development, of the person with mental retardation, it is also important to look at the willingness of the community, of the people around them in their environment, to accept them as one of their own. Studies on communication theory, emphasizing attitude change, are of importance in such an analysis. For example, the question can be raised: Does placement of a deviantly perceived individual in close proximity to normal citizens aid in the perception of the "deviant" as more acceptable or "less deviant" to the normal population? In 1973, Lin, a communication theorist, reviewed many studies and his observations on the cognitive - intellectual approach to attitude change are particularly interesting. Along with other researchers like Heider, Newcomb, Osgood, Tannenbaum, and Festinger, Lin sees humans as striving for consistency. He sees all of us as trying to fit information that we receive into our existing framework of knowledge. Failure to do that, to fit stimulus input into familiar patterns of knowledge, forces us into an unbalanced or dissonant state. The studies done thus far indicate that dissonance reduction can occur only if the condition causing the problem becomes familiar through increased contact. Thus, we cannot reasonably expect our fellow citizens to accept citizens with mental retardation if they have no contact with them.

Dissonance, or lack of balance, will not occur without a stimulus to cause it. Research into stress reduction, particularly studies of phobias (i.e., irrational fear of harmless objects or situations), demonstrate an example of dissonance reduction. Persons with phobias are cured by exposing them gradually to that which they fear (e.g., elevators). Through repeated contact they are eventually able to overcome their fear. Irrational fear of children and adults with mental retardation is surely due to lack of contact or familiarity with them, and can be overcome through social contiguity, by giving people opportunities to interact with others who are unfamiliar.

Benda (1960) and Webster (1970) found that children with Down's Syndrome reared at home tend to show lesser degrees of retardation than children with Down's Syndrome reared in institutions (Menolascino, 1970). We also know that people in institutions have a higher prevalence of psychotic and psycho-neurotic disorders (Menolascino, 1970). We know from Spitz and Bowlby and their classic world health organization study in the 40's that institutionalized infants failed to thrive when deprived of emotional nurturance in large hospital settings (Mulford, 1958).

In 1874 Samuel Gridley Howe had this to say in his report of the Superintendent to the Trustees of the Massachusetts School for Idiotic Children:

> Now the danger of misdirection in this pious and benevolent work is that two false principles may be incorporated with the projected institutions which will be as rotten piles in the foundations and make the future establishments deplorably defective and mischievous. These are, first, close congregation and, second, lifelong association of a large number of idiots. Whereas the true sound principles are separation of idiots from each other and diffusion among the normal population. For these and other reasons, it is unwise to organize establishments for teaching and training idiotic children upon such principles as will tend to make them become asylums for life. Even idiots have rights which should be carefully considered. At any rate, let us try for something which shall not imply segregating the wards in our classes, removing them from our sight and knowledge, ridding ourselves of our responsibility as neighbors, and leaving the wards closely packed in establishments where the spirit of pauperism is surely engendered and the morbid peculiarities of each are intensified by constant and close association of others of his class. (U.S. Dept of Health, Education, and Welfare, 1976).

Environmental Determinants

What does this research tell us? Not only does it guide us away from existing congregate residential models, it also identifies hallmarks which signal good future living environments. These hallmarks can be measured and controlled by service providers. They determine the type of behavior one is likely to get from human beings in certain environments. These environmental determinants are important, however, only if we want the person to leave the residence someday. If the residence is intended to be custodial, or lifelong, it really doesn't matter much whether we know why someone came to us for service, or what needs to be done to help them leave, since we do not intend for them to leave. Such a lifelong residential assumption exists today in most congregate care facilities, so that if one asks why a certain person is in the residence, the service provider responds with a patronizing smile and patiently reminds us that, after all, the resident is mentally retarded as though the

mental retardation is the cause for admission to the residence. Scant attention is paid to the reality that only 2% of people with mental retardation in the U.S.live away from their homes. The following are three environmental dete.minants which existing research, personal observation and experience suggest we should analyze in residential service development.

I. Distance of residence from natural home. This is a variant on the maxim, "out of sight, out of mind." The closer one is to one's home, the greater the contact with friends and relatives, the greater the sharing of information between parents and staff, and the greater the likelihood the person will return home. Parental awe (not respect) of agency professionals, is minimized as contact increases (cognitive dissonance is reduced).

II. Number of unrelated people living together. People who appear or behave differently are less conspicuous in the company of normal models. When the number of "different" people increases, so does the ease of identification and consequent aversion by normal counterparts (cognitive dissonance). Irrational fears of people are brought into stark relief, as witnessed by the cruel attacks on groups homes and their residents in the United States. People fear that their property value will decline when single and multiple family residences are mixed. Parental participation in programing outside the residence is less likely with large numbers of employees. The ability of parents to conceptualize and plan for return of the person to the natural home is more difficult when the environment bears the trappings of a medical facility,* or the employees use psychological jargon that is understood only by behavioral scientists. The ability of neighborhood families to physically accomodate their disabled neighbors in morning coffee/tea breaks, or in special human celebrations is reduced as the number of residents increases. Thus, integration is obstructed. The variety of adaptations in the physical structure necessary to adapt it to a wide array of disabilities sets the facility apart from the rest of the community.

III. Time away from home. Families or communities which lose a member reconstitute themselves after awhile. Different friendships, alliances, and other social relationships emerge, as Jan pointed out in his study of correctional system clients. Number of visits to the excluded member diminishes over time, as does the duration and intensity of contacts. It becomes more and more difficult to know what to say. The pathology of separation has been poignantly felt by human beings in times of war. Partly in response to this pathology we see junior executives in business and industry declining promotions which require a move and will separate/divide the family unit.

* "Professionalism" practiced as mystical rites with terminology, symbols or badges to separate groups, and buildings or equipment designed to shield in - competence is described by Wolfensberger (1969) in his overview of settings where persons with mental retardation are viewed as sick people, and by Goffman (1961) in his description of the medical service model.

The Residential Assumption

In 1977 Gunnar Dybwad shared these thoughts with members of the Third Asian Conference on Mental Retardation:

> Some of the members of this audience will have a voice in their respective countries with regard to the allocation of financial resources. Will you be seduced into spending vast monies for institutional buildings where people wil be segregated and confined and slowly but steadily deteriorate, or will you invest your funds in services to aid parents in coping with their problem of raising a retarded child? In a changing society buildings tie us down, while services are flexible and open to change.

While no one would argue that care of a disabled person must be the sole responsibility of parents or relatives, since in some cases such demands are clearly unreasonable, it is all too often true that placement of mentally retarded citizens out of their homes is due to the inadequate provision of parent support services. (Tizard, 1966) Crawford (1976) says that "it is services that are required by parents, not surveys, committees of inquiry, or other expensive excuses for inaction."

When one routinely expects or accepts residential placement for persons with mental retardation, he/she is engaging in the Residential Assumption. Residential services may be required by <u>all</u> citizens at some point in life, but they are intended to be provided for as short a time as possible. As the following framework illustrates, all residential services for all human beings fall into one of three categories, always based on the unique needs of the person requesting the service:

I. Need of the person. These residences are for physical treatment, e.g., a general hospital; or for emotional treatment, e.g., a psychiatric facility.

II. Need of the family. These residences exist to temporarily substitute for the natural family due to death, divorce, or other family disorder, and include single family foster homes or small respite care homes.

III. Need of the community. If the community in which an adult lives has inadequate vocational opportunities, one might have to stay in a motel, hotel, or be in a board and room facility or similar accomodation distant from the home, returning on weekends. Similarly, in extremely rural areas (e.g. Indian reservations, Eskimo communities), children might be required to leave their homes to live in boarding schools for a part of each week, or school year.

In all cases one knows why they left their home, and when they will return. Lifelong residence in large, congregate settings is not legitimized by any society for the general population and should not be legitimized for people with mental retardation. The one exception to this is the use of nursing homes for the elderly, a practice which is under heavy attack.

The purpose of most U.S. residential service systems, institutional and community, has been to provide treatment and training. Ostensibly such an effort has as its goal the eventual movement of the person back to the natural home (or an alternative in the community which is normal or near normal). But people do not return to their homes when the residential system ignore real reasons for admission, which may not be a need for treatment or training. When the clear reason for admission is family disruption, e. g., possible divorce, counselling or other services are rarely made available to the family. When a community does not have in place educational services for children, work training for adults, recreational programs, or in home occupational or physical therapy the presence of an institution 100 miles away leads to embracing that existing solution rather than developing local resources. Often what exists in present form becomes what is offered, a procrustean solution.

Conclusion

The following suggestions are offered as guidelines for the U.S. and other nations to avoid the Residential Assumption:

I. All family and individual support services should have been made available before a residence is sought.

II. All residences should be as small as possible.

III. Individualization. A specific reason(s) for requesting residential service should be identified and solutions to that problem(s) must be actively and creatively sought.

IV. A date for ending the residential program should be arrived at before admission.

V. A residence should be as close as possible to the community, neighborhood, or home where the person will live upon completion of the program.

VI. Partial residential services should be available. Rarely is 24-hour, seven-day-a-week residential service needed. Usually one day per week, a few hours per day, or a specified block of time is all that's required.

VII. Family involvment should be accomodated/encouraged. Service systems need not assume responsibility for parental functions which can continue to be met (e.g., providing transportation, managing medical/dental clothing needs, relating to school staff, etc.). It is not appropriate for staff to supplant the family by performing these functions.

VIII. Residential systems personnel should be evaluated and rewarded according to their ability to move people through and out of their systems, and the lasting nature of such movement.

Some people have said no defense need be made of normal environments on scientific grounds. Despite a history of more than a century of failure in our attempts to make institutions work, institution proponents continue to claim they haven't had enough time or they haven't been given adequate resources. Despite institutional failure they say abandonment of congregate care models should not occur until better options are operating. Unfortunately, funding for such options is not available since it is often expended to sustain the existing institutions. Strong evidence for the value of normal residences does exist, as does a body of research which seriously challenges, on scientific grounds, all congregate living environments. It is hoped such studies will help us to move beyond institutional systems prevalent in the western world, toward strengthening of the more normalizing environments, particularly the nuclear family.

The direction for the future in services to people with mental retardation may be a return to the past. Perhaps measurement of residence size (an environmental determinant) is more than a measure of normalization. Perhaps it is a measure of our humanity, our civilization. It may be that Ghandi was thinking of this when he was asked by reporters what he thought of western civilization. His reply was: "I think it would be a good idea."

STATEMENT OF TESTIMONY

ON THE

DEVELOPMENTAL DISABILITIES AMENDMENTS OF 1981

RESPECTFULLY SUBMITTED,

TO THE

SUBCOMMITTEE ON THE HANDICAPPED

COMMITTEE ON LABOR AND HUMAN RESOURCES

U.S. SENATE

THE HONORABLE LOWELL WEICKER, JR.
CHAIRMAN

NATIONAL ASSOCIATION OF STATE
MENTAL RETARDATION PROGRAM DIRECTORS

APRIL 30, 1981

The membership of the National Association of State Mental Retardation Program Directors consists of the designated officials in the fifty states and territories who are directly responsible for the provision of residential and community services to a total of over half a million mentally retarded children and adults. As a result, we have a vital stake in a variety of federal health, education and social welfare programs. In recent years, as states have begun to emphasize the development of a wide range of residential and daytime alternatives to large, publicly-operated institutions, the number, scope and complexity of federal assistance programs impacting on state mental retardation agencies has increased tremendously.

The Developmental Disabilities program is one small but important component of the federal government's array of assistance programs which impact on mentally retarded citizens. The state mental retardation agency serves as the designated unit to administer federal DD formula grant funds in over half of the states. In addition, since an esimated 65 percent of the estimated 5.4 million developmentally disabled persons requiring services have a primary diagnosis of mental retardation, even those state MR agencies which do not serve as the designated DD unit have an important concern for the success of the Developmental Disabilities program. For this reason, it seems both timely and appropriate to describe our experiences as state officials who have been intimately involved in the day-to-day operation of the program since its inception some ten years ago.

In our testimony, we will elaborate on our reasons for supporting an extension of the Act, with minor modifications and clarifications in the areas of program evaluation and special project grants. In addition, we will discuss the Association's views on several other issues which are likely to arise during the course of the Subcommittee's deliberations, including the application of provisions protecting the rights of institutional employees and the intent of the so-called "Bill of Rights" for developmentally disabled persons. Finally, we will outline our views regarding the relationship of the DD program to the Social Services Block Grant authority proposed by the Reagan Administration.

Need for Extension Legislation

Authorizations under the DD Act expire at the end of this fiscal year. Thus, it is imperative that Congress act swifty to prevent uncertainty in funding and disruption in the lives of the handicapped persons benfiting from activities supported through the Act. We urge the Senate Committee on Labor and Human Resources to report legislation extending the program by May 15, so DD authorizations will be considered during the development of the regular FY 1982 budget and appropriations measures.

As you know, the Reagan Administration has proposed splitting the functions of the DD Act by: (1) incorporating DD state grants for basic services and for protection and advocacy services (a combined total of $51 million) with eleven other human services programs into a $3.8 billion, Social Services Block Grant authority; and (2) consolidating DD special projects and University Affiliated Facilities funding (a total of $10.5 million) into a $61 million federally administered social services discretionary authority. Funding for both of these proposed, new "non-categorical" authorities would be reduced 25 percent below the aggregate FY 1981 funding level for the affected programs.

NASMRPD has long advocated granting state government increased flexibility in the management of federal resources on behalf of client populations whose needs cut across existing human services assistance programs. There is no question that the tangle of federal statutory and regulatory requirements has impeded the capacity of state agencies to effectively provide a comprehensive, coordinated array of daytime, residential and support services to mentally retarded and other developmentally disabled citizens. In a time of diminishing resources, states need more latitude to devise cost effective and appropriate service delivery mechanisms that fit the unique circumstances of their state system for serving such special populations as the developmentally disabled.

While consolidation of many human services state grant and entitlement programs into non-categorical block grant authorities may be helpful in reducing the cost and aggravation of assembling services, we believe that the special needs of developmentally disabled persons merit the reauthorization of the DD Act, as a separate and distinct statutory authority.

We justify this position on the following grounds. First, the Act was never intended to be a basic support program. When the Developmental Disabilities Program was initially authorized by Congress in 1970, the legislation was seen as a planning, coordinating and gap-filling mechanism which would assist consumer representatives, service providers and responsible state officials to make rational sense of the growing array of federal and state programs to finance and deliver services to a target population of some of the most severely handicapped persons in our society. In looking back over the past ten years, it seems clear that the DD program has not achieved the high expectations which many consumer advocates and professionals held in 1970. At the same time, the fundamental objectives which the original legislation addressed are, if anything, even more meaningful today than they were ten years ago.

Three years ago, Congress restructured the DD Program to provide a somewhat more targeted and clearly defined set of service objectives. The Association endorsed this change because: (a) it allowed each state greater flexibility to choose the service areas in which federal dollars are most needed, while at the same time requiring each jurisdiction to focus its federally supported activities on clear, attainable service goals; and (b) it established a viable relationship between the scope of the program's service objectives and the level of federal aid available to help meet these objectives. Because of the delay in promulgating regulations to implement the 1978 DD Act Amendments, there has not been sufficient time to test the promise of significant improvement in the program as a result of the restructuring of expenditure priorities.

Second, developmentally disabled persons, as a group, are certainly among the most needy citizens in our society--both in economic and social terms. Therefore, they frequently qualify for nearly all the major federal service and entitlement programs aimed at the poor and disadvantaged, including Supplemental Security Income, Medicaid, Title XX, Vocational Rehabilitation, Education, Maternal and Child Health, Food Stamps, Housing, and a variety of other programs providing federal assistance on a mega-scale to low income individuals. This year, for example, the federal government will expend nearly $4 billion on services and benefits to MR/DD persons. In contrast, only about $700 million will be expended through categorical programs aimed specifically at assisting handicapped children and adults (e.g., Education of the Handicapped; Vocational Rehabilitation; Developmental Disabilities; Maternal and Child Health and Crippled Children's programs). If we narrow our perspective to programs funded directly through the Developmental Disabilities Act, we find that the $60 million appropriated in FY 1981 constitutes only 1.6 percent of all federal dollars which will be expended on behalf of the DD target population this year.

From this perspective, folding the DD program into a block grant will do little to increase the resources available to assist a state in improving services to its MR/DD citizens. And, given the Administration's plans to reduce federal aid sharply and the fact that the block grant authority would be administered in most states by an agency which has few, if any, direct responsibilities for serving MR/DD clients, it seems almost certain that the federal government's relatively miniscule investment in attempting to assure that existing resources are properly accessed and coordinated on behalf of this multi-need population will be gravely imperiled.

Third, our experience with existing block grant programs reveals that disenfranchised populations, like the poor and disabled, do not get a fair share of the funds allocated. In the state and local arenas where block grant monies are allocated among competing interests, developmentally disabled persons become a low priority (if recognized at all). For example, a study conducted by the General Accounting Office during the early days of the General Revenue Sharing Act found that less than 1/2 of one percent of the federal funds were being expended on behalf

of the handicapped. Similar findings emerged from reviews of HUD's Community Development Block Grant Program and Labor's CETA programs.

For the above reasons, we support a three-year extension of a separate Developmental Disabilities Act, with several minor modifications and clarifications as discussed below. Since we propose a minimum three-year extension, the Association suggests the following authorization levels:

	(in millions)		
	1982	1983	1984
Section 131 State Formula Grant	$60	$70	$80
Section 113 State P & A System	15	15	15
Section 123 UAP	12	15	18
Section 145 Special Projects	12	15	18

Each of these authorization levels is at or substantially below the levels for fiscal year 1981 contained in P.L. 95-602. However, the authorization levels allow for modest growth when compared to actual fiscal year 1981 appropriation levels.

Proposed Revisions

Generally, we support continuing the DD program as it is currently structured. However, in an effort to eliminate specific problems which have arisen since the enactment of the 1978 amendments, we recommend the following, relatively minor modifications in the present Act:

Evaluation. The first involves a revision in the evaluation requirements under the Act to: (1) clarify the Council's responsibilities for assessing the overall impact of the federal-state program; and (2) develop comprehensive, statewide, client-based evaluation systems and to substitute in its place an optional program to assist states interested in developing such capabilities.

In 1975, Congress amended the Developmental Disabilities Act to require that each state develop a comprehensive, statewide system for evaluating services provided to developmentally disabled persons. The law stipulated that a state's evaluation system had to be based on data derived from individual habilitation plans of persons receiving services funded under the Act. Furthermore, the law conditioned future receipts of federal formula grant assistance under the Act on the planning and development of such a system.

Under the 1975 legislation, states were required to submit their evaluation implementation plans by March 1978 and have the system fully implemented by March 1980. However, the deadlines for completing these steps were delayed under the provision of P.L. 95-602 (until October 1, 1980 for submittal of the plan and two years later for full implementation of the system).

States have long recognized the need for a system of evaluation for the developmentally disabled and, even before the 1975 amendments, some states had begun exploring various methodologies. Since the 1978 amendments to the DD Act, states have been attempting to comply with guidelines developed under Section 110 of the Act. Although most states have developed a time-phased plan for the implementation of such a system by October 1, 1980. many are concerned that they face real difficulties in carrying out the latter and spirit of the existing statutory requirements.

Since the enactment of the 1975 legislation mandating the development of statewide evaluation systems, the most perplexing question has been the appropriate scope of such a system. Indeed, the original Senate version of the 1974 Developmental Disabilities Amendments (S. 3378) would have required the comprehensive evaluation system to be implemented on behalf of all developmentally disabled clients supported under any federally assisted program. Almost identical language was contained in the successor bill passed by the Senate in 1975 (S. 462). However, when the bill went to conference with the House, the applicable scope of the comprehensive evaluation system was restricted to clients receiving services funded under the Act. This change, although clearly sensible in terms of Congressional jurisdiction, highlighted the central problem which has plagued drafters of evaluation system specifications ever since: i.e., on the one hand, it makes very little sense to institute a client-based evaluation system which does not deal with a system of service (which the federal formula grant program, standing on its own, clearly is not); and yet to interpret the provisions of Section 110 to extend beyond programs funded directly under the Act over-reaches the original statutory intent of Congress and imposes on the states potential costs which could easily exceed the total federal DD allotments of many states.

The guidelines promulgated by the Administration to implement Section 110 reflect a number of inadequacies, both in the proposed evaluation system specifications and in the current state-of-the-art. Among the problems posed by these guidelines are that they: (1) gloss over the lack of valid, reliable and standardized assessment tools for measuring client progress, for program quality and for determining the "least restrictive environment"; (2) assess a client's achievement on the number of objectives accomplished under individualized habilitation plans, which is inappropriate because, by definition, such plans are individualized and not standardized for aggregation; and (3) emphasize the collection of detailed, longitudinal data on every client which may not only be beyond the current state-of-the-art but also beyond the budget of the state agencies responsible for implementing the requirement.

In summary, there is a number of technical, economic, and political constraints which face the states in attempting to implement the evaluation system mandated under Section 110 of the Act. One does not have to be opposed to methodologically sound, comprehensive evaluation of services to developmentally disabled persons in order to conclude that the current strategy for implementing the requirements of Section 110 is doomed to failure, unless major changes are mandated.

We urge the Committee to adopt modifications in statutory language recommended by the Consortium Concerned with Developmental Disabilities. In drafting this language CCDD tried to accomplish two objectives. First, the proposed language expands the provisions of Section 133(b)(2)(D) to require states to assess the impact of the federal-state DD program, as an intrinsic part of the planning process. States would be required under the modified language to document how new program funds have been accessed, what state policies have been changed as a result of council activities, in what manner council activities have improved the scope and quality of services, and how councils have contributed to enhancing the capacity of the state system of services. It also would require that states assess existing or planned statewide evaluation systems and collect demographic data on people served under the DD forumla grant program.

Second, the proposed language encourages states, at their option, to develop management information systems using client-based data, without superimposing a federal system of specifications which frequently do not meet the states' needs. The Secretary would be authorized, under the revised language of Section 110 of the Act, to reserve a portion of future state allotments (up to ten percent of the total allotment base) for the purpose of assisting states interested in improving client-based management information and evaluation systems. To assure that no state would be negatively impacted by this new provision, however, reservations for such special allotments would only apply to the increased portion of the total Part C allotment based after September 30, 1981.

Special Projects

The overall aim of the proposed statutory modifications in the special project grant authority is to refocus existing priorities for expending such discretionary funds and to offer the interested public expanded opportunities to participate in the process of determining how future funds are committed. As such, these revisions are intended to rectify past criticisms (by GAO and others) that the Administration on Developmental Disabilities seemed to lack a coherent strategy for obligating project grant funds in a manner designed to leverage significant change within the field of services to developmentally disabled persons.

More specifically, the proposed amendments would: (a) require the Secretary to publish a plan for obligating special project grant funds, solicit public comments and explain the Department's rationale for choosing the types of projects selected for funding; and (b) replace the existing "laundry list" of fundable project areas (contained in Section 145(b)) with a new list of preferential areas, oriented toward activities or functions which can be carried out most efficiently and economically through projects with a multi-state or nationwide focus.

Language also is included which would require the Secetary to give preference to projects which are part of a broader effort by responsible state and local agencies to expand and improve services to developmentally disabled persons. Too often in the past, national and regional significance projects have been funded without a careful prior analysis of their relationship to general attempts by public agencies in the affected catchment area to improve services on behalf of the target population. As a result, such projects have frequently run their course without having any significant impact on the manner in which services are delivered within the area. While the proposed language offers no panecea for solving this problem, at least it would focus attention on whether any given project was consonant with state/local service delivery goals and offered promise of having a substantial impact on efforts within the target jurisdiction(s) to address outstanding delivery issues.

Furthermore, such cooperative demonstration projects offer a realistic means of deploying Section 145 funds so that they will have a "multiplier effect". Thus, rather than using the finite dollars available under Section 145 to provide support for all aspects of an isolated demonstration project, the proposed language would require the Secretary to give special preference to cooperative demonstration projects in which responsible public agencies assume a significant share of the cost of the project or closely related activities. By employing this method, it should be possible to stretch project grant dollars so they have a considerably broader impact.

Finally, the proposed language includes provisions designed to encourage ADD to enter into cooperative agreements with other federal agencies "which show promise of increasing the access of developmentally disabled persons to generic housing, transportation, vocational training and placement, employment, health, social services, education and other human services..." Again, the main aim of such projects would be to improve federal interagency efforts on behalf of developmentally disabled persons and obtain maximum impact from the limited Section 145 dollars available in any fiscal year.

Other Issues for Consideration

There are at least two other major issues which are likely to arise during the Subcommittee's consideration of legislation to extend the Developmental Disabilities Act: (1) whether to alter in any way the Act's present provisions regarding the protection of the rights of individuals employed in MR/DD institutions who may be adversely affected by deinstitutionalization efforts (Section 133(B)(7)(B)); and (2) whether to clarify the scope of applicability of the so-called "Bill of Rights" provisions of the Act (Section 111). With regard to these issues, we are opposed to amending the existing language of the Act; instead we feel that the Subcommittee should clarify, in its report accompanying extension legislation, the original intent of Congress in adding these provisions to the Act. The proposed regulations issued by the Department of Health and Human Services on May 9, 1980 to implement the 1978 amendments illustrates the fact that

there is a great deal of confusion concerning Congress' original intent, as it affects these two key provisions of the 1975 amendments.

The Department's proposed rules reflect an underlying assumption that several provision of the Act mandate action which extend, not only to programs and services funded under this legislation, but to all other activities provided to developmentally disabled clients through the designated state administering agency--regardless of the source of public support (federal, state or local).

The proposed regulations treated Sections 111 and 133(b)(7)(B) of the law as though they were sweeping legal entitlements, rather than program specific conditions for receipt of federal assistance. Inherent in every grant-in-aid program, of course, is a *quid pro quo* relationship between the federal government and the states (i.e., to qualify for financial assistance a state must agree to conform to certain minimum statutory and regulatory conditions of participation). However, the productivity in this partnership is dependent on the establishment of a reasonable balance between the "quid" (grant conditions) and the "quo" (federal assistance). When these two factors are out of balance, the partnership fails and the inevitable losers are the intended beneficiaries of the program.

In 1975, Congress amended the Act to add a series of "findings" regarding the rights of developmentally disabled persons (Section 111). These rights encompassed the right to appropriate treatment and habilitative services in the least restrictive setting, as well as several other specific rights (e.g., an adequate diet; appropriate medical/dental services; freedom from physical and chemical restraints; and visitation rights). Regulations implementing the 1975 amendments included, in the preamble, the statutory language of Section 111 of the Act. At that time, there was no mechanism incorporated into the rules to assure that Section 111 rights were implemented.

The May 9, 1980 regulations, however, would have required a state to provide assurances that no "federal, state or other public funds..." will be expended on "any activity which serves persons with developmental disabilities that is not in compliance with these rights" (Section 1385.3). The preamble to the May 9 rules outlined the Department's rationale for taking this position. The 1978 amendments, the Department noted, revised Section 111 to "require implementation of the provision." Furthermore, the Department took the position that the rights guaranteed under Section 111 extended to all publicly funded services to mentally retarded clients (federal, state and local), not just those programs funded in whole or in part through the Developmental Disabilities Act. Later, the Department backed away from this position in final draft regulations, which were on the verge of publication when they were withdrawn on January 21, 1981 by the incoming Reagan Administration.

The U.S. Supreme Court, in its April 20, 1981 decision in the case of Pennhurst State School and Hospital, et. al. v. Halderman

et. al. found that Section 111 is "too thin a reed to support the rights and obligations read into it by the [appeals] court..." Based on a review of the legislative history leading up to the inclusion of these provisions in the 1975 amendments, the Court added, "the closest one can come in giving Section [111] meaning is that it justifies and supports Congress' appropriation of money under the Act and guides the Secretary in his review of state applications for federal funds." We believe that the Supreme Court's reading of Congress' original intent is accurate and, therefore, urge the Subcommittee to include clarifying language in its report on the legislation to eliminate any further ambiguity.

In our opinion, the scope of applicability of the Act's provisions also has been confused in regard to the protections afforded institutional employees when a state is engaged in placing facility residents in less restrictive and more appropriate residential settings. Section 133(b)(7)(B) of the Act requires, as a condition of participating in the federal/state developmental disabilities formula grant program, that a state provide "for fair and equitable arrangements...to protect the interests of employees affected by actions under the plan to provide alternative community living arrangement services..." Existing HHS regulations, promulgated in January, 1977, simply restate the statutory language. The May 9, 1980 proposed regulations, however, were considerably more explicit.

Once again, the critical question is the applicable coverage of this provision of the Act. Section 1386.51(a) of the proposed regulations paraphrased the statutory requirement, by specifying that "the State plan must provide for fair and equitable arrangements to protect the interests of all employees affected by actions under the plan to provide alternative community living arrangements" (emphasis added). The regulations, however, do not explain when the interests of employees can reasonably be judged to be "affected by actions under..." a state's plan. In many states, activities supported directly through the Act make up only a miniscule part of efforts to expand and improve alternative community living arrangements on behalf of developmentally disabled persons.

We believe that in adding Section 133(b)(7)(B) to the Act in 1975, Congress intended to assure that the interests of institutional employees would be protected in all deinstitutionalization activities wholly or partially funded under the Act. However, there was no explicit or implied intent to extend this requirement to all deinstitutionalization efforts undertaken by state government, regardless of the source of funding. Nonetheless, this is precisely the position the Department took in both its proposed and final draft regulations.

The seriousness of the situation is underscored by the fact that one state (Virginia) already has elected to withdraw from the federal-state DD program, in part, because the potential liability it would incur through the extension of employment safeguards to all existing institutional employees would far exceed its federal DD allotment. The reports we have received indicate that a number of other states are likely to follow suit if existing law is interpreted in the manner proposed by HHS in the recently withdrawn regulation.

Our Association favors equitable arrangements for protecting the interests of institutional employees who are affected by plans to close or phase down the population of existing state residential facilities. However, unless federal DD dollars are used in whole or in part to finance such deinstitutionalization activities, we do not feel that the provision of Section 133(b)(7)(B) should be interpreted to require states to afford such protections to its employees. The proper forum for discussion of such labor-management issues is through existing collective bargaining procedures which are currently in effect in most states.

For the reasons discussed above, our Association believes that it is imperative that the Subcommittee clarify in report language its intent regarding the scope of applicability of employee protection afforded under the Act.

Conclusion

In summary, the Association supports a three-year extension of the Developmental Disabilities Act, as a discrete set of federal programs. We believe modifications are needed in existing statutory requirements governing evaluation and special projects. We also recommend clarification in the Committee's report regarding existing provisions of the Act related to the so-called "Bill of Rights" and employee protections, so that it is clear that these provisions are only intended to extend to activities supported wholly or partially through federal DD funds.

(Note: In the interest of economy, the text of the U.S. Supreme Court's decision on April 20, 1981, in the case of Pennhurst State School and Hospital, et. al. v. Halderman et. al., as published in the "Law Week," April 21, 1981, was retained in the files of the committee where it may be researched upon request.)

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in the public service

Statement
to the
Subcommittee on the Handicapped
of the
Senate Labor and Human Resources Committee

on the

Developmental Disabilities Amendments of 1981

On Behalf of

The American Federation of State, County and
Municipal Employees, AFL-CIO

By

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May 5, 1981

On behalf of AFSCME's more than one million members, approximately 250,000 of whom work with the mentally and developmentally disabled in community-based and congregate living facilities across the nation, I am submitting for the record AFSCME's position and concerns regarding the Developmental Disabilities Amendments of 1981. AFSCME has long been committed to a balanced system of high quality institutional and community services for all people who need them.

As an International Vice President of AFSCME, President of the New York State Civil Service Employees Association, Member of the President's Committee on Mental Retardation, and a 13-year employee of the West Seneca Developmental Center, I have come to know firsthand the problems of the developmentally disabled, and the need for a strong federal commitment on behalf of this truly needy and highly vulnerable population.

A major goal of this federal commitment has been a planned, rational transfer of certain resources from large institutions into the community. The 1975 Developmental Disabilities Assistance and Bill of Rights Act (P.L. 94-103), the extension and amendments of 1978 (P.L. 95-602), and the proposed extension and amendments of 1981 recognize that an important element of any such rational transfer of resources is the requirement for planned and substantive employee protections. Employee protections requirements assure not only that the interests of workers directly affected by changes in public service delivery policies will be protected, but that:

1. Planning for community services will include such issues as continuity of care, career ladders in the community, recruitment qualifications, therapeutic and uniform supervision, and the prevention of high rates of employee turnover.

2. Developmentally disabled people will not be deprived of the services of skilled, experienced and dedicated workers as a result of having moved from institutions into the community.

Rather than promote the hasty, unplanned phase-down of institutions and the haphazard generation of community programs of widely fluctuating quality and longevity, the Federal Developmental Disabilities Program has set the stage for sound and comprehensive planning for institutional as well as community services.

AFSCME's experience in states where employee protections have been negotiated has been positive and very much encouraging. In virtually every instance, the interests of the developmentally disabled -- and the service system as a whole -- have been considerably advanced. In terms of long-range outcomes, attention to employee protections and the early involvement of employee representatives in the planning process, has set a positive and healthy climate for continuing cooperation.

- In my home state of New York, CSEA/AFSCME Local 1000, the Governor's Office, and the State Office of Mental Retardation formed a consortium to retrain institutional workers for new upgraded career ladder positions in both institutional and community settings (see Attachment A). Attention to employee protection issues has led to ongoing joint initiatives to resolve matters such as insufficient staffing ratios, institutional and community working conditions and productivity.

- In Rhode Island, Employee Protections Negotiations resulted in the establishment of state-run community residential and day services for the developmentally disabled (Attachment B). Experienced institutional workers were permitted to follow their clients into the community, new training programs were instituted, and layoffs were averted. According to state officials, morale increased and the financial impact of having implemented these protections has been zero.

- In Maine, AFSCME has worked closely with the Administration of the Pineland Developmental Center to devise a personnel schedule which enabled that facility to comply with a Court Consent Decree. Further negotiations established an innovative apprenticeship and career ladder training program for direct care workers. Together, the State and AFSCME succeeded in securing $450,000 in federal training monies to fund the program (Attachment C).

- In Michigan, the State and AFSCME negotiated a proposal for state-run community programs which was submitted to the U.S. Department of Health and Human Services for Medicaid waiver approval. While approval and funding have not yet been obtained, a climate was set for future cooperation and joint planning activities.

While significant progress has been achieved as a result of employee protections requirements in the Developmental Disabilities Assistance and Bill of Rights Act, application of these provisions by the Department of Health and Human Services has been inconsistent and at odds with legislative intent. In the preamble to the proposed January regulations, as well as in guidance given to State Planning Councils, the Department has indicated that states may ignore their responsibilities under 42 U.S.C. 6063(b)(7)(B) merely by failing to designate community living arrangement services as a priority service. Such an interpretation creates a loophole through which states might seek to avoid their responsibilities under the Act to the detriment of the developmentally disabled and those who serve them.

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In 1979 and 1980, for example, the Massachusetts State Plan included the establishment of community living arrangement services as the top priority. For 1981, however, the establishment of community living arrangement services disappears as a priority service. The state plan for 1981 explains the absence of employee protections as follows:

> "Instructions for the FY 1981 Developmental Disabilities state plan indicate that those councils which have chosen priority service areas other than 'alternative community living arrangements' need not complete this paragraph (employee protections) of the Plan." (p. 487)

When questions arose regarding Nebraska's compliance, HHS officials reportedly advised that state simply to change designation of its priority service from community living arrangement services to some other area. Merely by calling their activities by another name, state officials were advised that they could circumvent the letter and intent of the law.

What is required is clear guidance from Congress directing the Department of Health and Human Services regarding the application of U.S.C. 42 Section 6063(b)(7)(B). The Act requires that the state plan must provide arrangements "to protect the interests of employees affected by actions under the plan to provide community living arrangement services" (emphasis added). Because the primary purpose of the Act is to promote planning and coordination of services to the developmentally disabled, any activity under the state plan which promotes the establishment of community living arrangement services would require the provision of protective arrangements for employees. Nothing in the language or history of the Act conditions a state's employee protections obligations on the designation of community living arrangements as a priority service in the State Plan.

Arrangements such as those described under Section 6063(b)(7)(B) are not intended as an impediment to deinstitutionalization. On the contrary, when states have adhered to the employee protections provisions of the Act and involved employee representatives in devising such arrangements, the results have been uniformly beneficial and the costs to those states negligible. The administering agency, rather than attempting to create loopholes, ought to be encouraging states to include staffing and personal issues in the early stages of service planning. As can be seen by Attachments A, B and C, the states remain free to devise protective arrangements according to local requirements and priorities.

Consequently, AFSCME urges the Committee to direct the Department of Health and Human Services to instruct State Planning Councils through regulations, guidelines and other official communications that the obligation to provide employee protections occurs whenever a state expends funds, or takes any other actions, under the Act to provide community living arrangement services, irrespective of whether community living arrangement services have been designated as a priority service under the Act.

Two other issues of concern to AFSCME include Special Projects Grants and the meaning of "least restrictive setting."

Special Project Grants - Section 6081 of the Act authorizes the Secretary to award special project grants for various purposes. In order to assure the retention and upgrading of experienced direct service workers, AFSCME recommends that a minimum of 25 percent of the funds awarded under this authority be earmarked for joint labor/management programs to create community-based career ladders, and the training or retraining of state institutional non-professional employees for jobs in connection with the provisions of alternative community living arrangement services.

Least Restrictive Setting - Section 6010 of the Act (the "Bill of Rights") indicates that developmentally disabled individuals have the right to treatment and habilitation services "in the setting that is least restrictive of the person's personal liberty." This has been misinterpreted to mean virtually any setting other than a state facility. The issue of "least restrictive setting," of course, is relative, and involves questions of degree of disability, individual needs for habilitation, protection against self-destructive behavior and environmental hazards, and the requirements of each person's individual treatment plan. It is incorrect to assume that large institutions by definition deprive developmentally disabled people of a more "normal" or "less restrictive" mode of life as opposed to nursing homes, community residences, single room occupancy hotels, bus stations or parks.[1] Treatment is a medical rather than a legal or administrative decision. Clarification by Congress on this issue would provide needed guidance to council officials and state program administrators as they develop long-term plans for the developmentally disabled.

On behalf of more than one million AFSCME members, I appreciate the opportunity to submit this statement for your consideration.

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[1]See D. Balla, "Relation of Institution Size to Quality of Care: A Review of the Literature," 81 American Journal of Mental Deficiency, 117-124 (1976). Also, H. Menninger, "Issues in the Development, Programming, and Administration of Community Residential Facilities For Developmentally Disabled Persons: A Review," Health Care Financing Administration (October, 1980).

STATE OF NEW YORK

ATTACHMENT A

MEMORANDUM OF UNDERSTANDING BETWEEN
THE CIVIL SERVICE EMPLOYEES ASSOCIATION AND THE
OFFICE OF MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES
AND THE GOVERNOR'S OFFICE OF EMPLOYEE RELATIONS
FOR A DEMONSTRATION PROJECT TO RETRAIN STATE EMPLOYEES
FOR COMMUNITY SERVICE PROGRAMS

I. PURPOSES

The purpose of this agreement is to facilitate the development, implementation, and evaluation of a retraining demonstration project, under the joint sponsorship of The Civil Service Employees Association, the Governor's Office of Employee Relations, and the Office of Mental Retardation and Developmental Disabilities, designed to retrain employees for assignment to State Community Service programs for the mentally retarded and developmentally disabled. Further, the results of the evaluation of this demonstration project will provide the basis for the development of a model training program, for further implementation, under joint sponsorship of The Civil Service Employees Association, the Governor's Office of Employee Relations, and the Office of Mental Retardation and Developmental Disabilities; and to assure that those employees who are prospectively facing discontinuity of employment due to the expansion of community-based care of the mentally retarded and developmentally disabled be provided the opportunity for retraining as one means of successful program development.

II. LABOR/MANAGEMENT COMMITTEE

There shall be a Labor/Management Committee composed of the President of the Civil Service Employees Association, the Director of the Office of Employee Relations, and the Commissioner of Mental Retardation and Developmental Disabilities, or their respective designees, to oversee the development, implementation and evaluation of the demonstration project.

Appropriate number of personnel will be employed as direct staff to the Labor/Management Committee to carry out the activities of this project. The members of this Labor/Management Committee are to develop and facilitate the achievement of project goals and objectives within their own organizations, thereby ensuring mutual efforts among the participating organizations.

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The policies established by the Labor/Management Committee will be implemented by a Project Coordinator. The Labor/Management Committee will be responsible for the definition and development of the Project Coordinator's function and job description, as well as the recruitment, selection and hiring for this position. This person will be directly accountable to the Labor/Management Committee to ensure that the project objectives are met in a timely manner. All recommendations submitted to the Labor/Management Committee by the Project Coordinator for decision making will require group unanimity.

III. PROJECT PLANNING, IMPLEMENTATION, EVALUATION AND FUNDING

A. Planning

The Labor/Management Committee will be established upon signature to this Agreement of all concerned parties. Their first task will be to design and jointly approve the project proposal.

Plans, including workplan and timetable for proposal implementation will be developed by the Project Coordinator for review and approval by the Labor/Management Committee prior to implementation.

Members of the Labor/Management Committee shall share as necessary any appropriate available data on labor force characteristics, manpower and employment trends, new program developments and related areas. The Labor/Management Committee shall also be consulted on the recruitment and selection of outside experts or other organizations who may be hired.

B. Implementation

The Project Coordinator will be responsible for the direction and completion of the project's goals and objectives in accordance with the approved plan and timetable. This is to include training needs assessment, curriculum/materials development, evaluation, and administration of the project. Such efforts are to be carried out in conjunction with the President of The Civil Service Employees Association, the Director of the Governor's Office of Employee Relations, and the Commissioner of the Office of Mental Retardation and Developmental Disabilities, or their designees, in order to maximize coordination of all training efforts and resources of these organizations.

The Project Coordinator will establish a project advisory committee, in the project planning phase, to consist of a representative group of potential trainees (CSEA members - 50 percent), and non-CSEA members (management representatives - 50 percent) from the participating agencies. The purpose of this committee will be to advise the Coordinator in planning for achievement of the project goals. The advisory committee will

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be consulted, when appropriate, about the design and content of the instruction. Their input will be sought as part of the ongoing assessment of instruction in the post evaluation of the training.

The Coordinator may draw upon other experts and agencies with the prior approval of the Labor/Management Committee as determined to be necessary and may meet in subcommittee by organization (CSEA, OER, OMRDD) as appropriate and necessary to the achievement of project goals.

All experts engaged to perform work essential to the completion of project tasks shall be subject to existing State requirements for hiring of consultants, including competitive bidding provisions when indicated.

C. Evaluation

The Project Coordinator will submit a plan to the Labor/Management Committee for a systematic evaluation in order to assess impact and to provide essential information as a basis for decision making. A major objective in this evaluation is to improve the content and methods of instruction in terms of the training needs essential to effectively retrain employees for job assignments in State Community Service programs. In addition to the evaluation efforts of the project staff, should the Labor/Management Committee so desire, an allocation will be made in the project budget for an independent project evaluation, by an outside expert, prior to finalization of the training model for further implementation.

D. Staffing and Funding

All parties agree to solicit funds to support sufficient staff to carry out the aforementioned objectives and to explore the availability of federal funds. In addition, it is agreed that the Office of Mental Retardation and Developmental Disabilities will submit the project proposal to the New York State Department of Social Services for Title XX funding. Further, it is agreed that the Civil Service Employees Association and the Office of Mental Retardation and Developmental Disabilities will contribute equal funds, if necessary, for any required matching funds to obtain federal funding for the project.

THE EXECUTIVE BRANCH OF THE
STATE OF NEW YORK

Meyer S. Frucher, Director
Governor's Office of Employee Relations

James E. Introne
Commissioner of Mental Retardation
and Developmental Disabilities

THE CIVIL SERVICE EMPLOYEES
ASSOCIATION, INC.

William L. McGowan, President

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ATTACHMENT B

MEMORANDUM OF AGREEMENT

In this agreement made by and between Rhode Island Council 94, American Federation of State, County and Municipal Employees, AFL-CIO, on behalf of Local 1291, and the State of Rhode Island, the parties agree as follows:

1. It is recognized that the policy and practice of the Department of Mental Health, Retardation and Hospitals (MHRH) is to provide services to all clients in the least restrictive setting, whenever possible, including developing individualized plans for transfer from State institutional settings to community settings (deinstitutionalization plans).

2. It is further recognized that in developing such deinstitutionalization plans, the Department will comply with any and all provisions of the collective bargaining agreements of the various bargaining units potentially affected by said plans, as well as complying with (DDC-SPO-80-003) entitled: "Employee Protections as Related to Deinstitutionalization."

3. The agreements set forth below shall be an addendum to and part of the existing collective bargaining agreement between the parties. The parties herein specifically agree as follows:

4a. No Ladd Center employee will be terminated, reduced in pay or class, nor laid off due to deinstitutionalization plans.

4b. Reductions in employee numbers at Ladd Center will be made through the normal attrition process and in compliance with the provisions of the collective bargaining agreement between the parties.

4c. Provisions for retraining of institution staff to be transferred will be the responsibility of MHRH as appropriate, and every effort will be made to access Title XX funds.

4d. Ladd Center employees who remain State employees and who are transferred to State operated Community facilities due

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to deinstitutionalization plans will be guaranteed an opportunity for the continuation of collective bargaining rights, including pensions, seniority, vacation, health insurance and other benefits.

4e. Proper notifications of deinstitutionalization plans affecting individual employees or groups of employees will be made in accordance with existing collective bargaining agreements.

4f. Efforts will be made to communicate openly and to generate common understanding and agreements with appropriate labor organizations potentially affected by deinstitutionalization plans.

4g. Division of Retardation plans and other MHRH plans affecting Ladd Center clients will contain provisions regarding the above agreements from this date forward.

5. Notwithstanding items 4a. and 4b. in the Memorandum of Agreement, it is understood that if any employee refuses a new assignment in accordance with the provisions of the Master Contract then such employee may be laid off.

FOR THE STATE OF RHODE ISLAND

Governor

Director of Administration

Director, Department of MHRH

Asst. Director, Labor Relations

FOR COUNCIL 94, AFSCME, AFL-CIO

Executive Director

President, Council 94

International Representative, AFSCME

Vice President, Local 1291

Dated:

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ATTACHMENT C

R.I. UNION OFFICIALS COOPERATE

In the next year and a half, hundreds of Ladd Center residents will move from the institution to group homes and apartments across Rhode Island, as part of the state's four-year effort to create a comprehensive system of community alternatives. By 1984, Ladd could serve as few as 100 retarded persons, if plans go as expected.

The Department of Mental Health, Retardation and Hospitals (MHRH) and Council 94 of AFSCME, which represents Ladd employees, have now reached an agreement guaranteeing that no Ladd employee will be laid off, fired or reduced in grade because of Ladd deinstitutionalization plans. Reached after a lengthy period of negotiation regarding the process through which personnel will be reassigned as Ladd residential buildings are closed, the Department has agreed, in writing, that employees will not lose their jobs because of program reorientation either at Ladd or any other MHRH facility.

Other state activities focusing on the relocation of institutional staff include: (1) The establishment of a pilot community workshop for 65 Ladd residents, staffed by fifteen Ladd School employees who have volunteered for the assignment. MHRH officials are citing the program as a model for how the reassignment of staff can be made without turmoil. (2) The development of HUD-financed apartments to serve 20 to 40 Ladd residents (see the November, 1980 issue of *New Directions*). Once they are opened, the apartments will be operated by Ladd staff. According to Dr. Robert Carl, Associate Director of the Department, "This is a cost effective way of establishing community programs while guaranteeing the jobs of employees." (3) The development of plans to enable Ladd employees to become community service case managers.

For additional information, contact: *Robert L. Carl, Ph.D., Associate Director, Division of Retardation, Aime J. Forand Building, 600 New London Avenue, Cranston, Rhode Island 02920.*

AFSCME INITIATES APPRENTICE PROJECT

In a recent interview with the Editor of *New Directions*, the national headquarters staff of the American Federation of State, County and Municipal Employees (AFSCME) described some of the Federation's current activities and goals as they relate to the phasedown of public residential facilities serving mentally retarded and mentally ill clients.

One such activity is the apprenticeship training program, administered by AFSCME Career Development, Inc., a non-profit subsidiary of the Federation. The overall goal of this project, which is supported by the Department of Labor's Bureau of Apprenticeship and Training, is to develop standards and procedures for apprenticeship programs in occupational categories employed by state, county and municipal governments.

Currently, according to Assistant Project Coordinator Lettie Atkins, the project staff is assisting AFSCME councils and local affiliates to develop standards for paraprofessionals providing care to mentally retarded persons. Efforts also are being directed at the preparation of curricular materials for classroom and on-the-job training designed to upgrade and reorient the skills of such paraprofessionals. For example, at Pineland Center, Maine's largest public residential facility for the mentally retarded, direct care employees are receiving training to prepare them for more active participation in programming for clients within the institution as well as other state-supported day programs.

According to Mr. Louis Nayman, AFSCME's Health Care Specialist, one of the Federation's long range goals is to get more AFSCME members involved in the service-delivery planning process, both before and during the policy development stage (e.g., participating in policy task forces, state and regional developmental disabilities councils and national advisory groups, such as the President's Committee on Mental Retardation).

A second major objective is institutional reform, including: (1) securing adequate funding from state legislatures to maintain appropriate services; and (2) expanding staff training opportunities to enable employees to provide better care. The Federation, he said, stresses the use of master contracts between management and employees to ensure the quality of care.

In regard to the placement of retarded persons into community-based residential alternatives, Mr. Nayman highlighted the following major problems faced by facility employees when they are relocated in community programs:

- lower pay and benefits for doing the same job;
- nonexistent or inadequate career ladders;
- lack of access to public transportation (facilities in rural areas);
- lack of staff training and resources to perform their jobs adequately; and
- understaffing and forced overtime at many community facilities.

To alleviate some of these problems, Nayman noted several states have taken steps over the past few years to protect the interests of institutional employees. He cited the activities currently underway in New York, Illinois, Maine, Rhode Island and Michigan as examples of positive attempts to deal with employee grievances associated with deinstitutionalization (see articles on pp. 1, 2 and 3).

Another major problem associated with deinstitutionalization, Mr. Nayman added, is the placement of clients before community service systems are properly developed. AFSCME has issued several publications on this subject. The most recent is entitled, "Patients for Sale: How Private Profit Exploits the Mentally Disabled and How the Public Sector Can Solve the Problem". Prepared by AFSCME's Department of Public Policy Analysis, the monograph reviews the problems which have been encountered in a number of states when mental patients were "dumped" out of state facilities with inadequate planning and resources. It is currently in draft form and is expected to be available for general distribution by June, 1981.

For additional information on AFSCME policies and activities, contact: *Louis M. Nayman, Health Care Specialist, AFSCME, 1625 L Street, N.W., Washington, D.C. 20036.* For more specific details on the apprenticeship program, contact: *Ms. Lettie Atkins, Career Development, Inc., at the same address.*

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tuberous sclerosis association of america, inc.
telephone (617) 878-5528
A NON-PROFIT ORGANIZATION

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May 5, 1981

Honorable Lowell P. Weicker, Jr.
Chairman, Subcommittee on the Handicapped
313 Russell Senate Office Bldg.
Washington, D.C. 20510

Dear Senator Weicker:

We could write a book on P.L. 94-103 stating countless improprieties fostered and implemented under this legislation. However, this is not necessary since the G.A.O. has already submitted to the Senate Subcommittee on the Handicapped such a report captioned, "How Federal Developmental Disabilities Programs Are Working", HRD-80-43, dated February 20, 1980. We humbly ask that every member of both the House and Senate Committees responsible for the future of developmental disability legislation study the G.A.O. Report well.

Under present legislation, P.L. 95-602, the politely worded recommendations of the G.A.O. summarized at the end of each chapter become blatant violations of the law. Since the implementation of P.L. 95-602 (FYs beginning October, 1978) nothing has changed except on paper.

The new non-categorical definition in which the many previously unlisted developmental disabilities saw hope for recognition and aid is only a paper-mache. In the world of reality, P.L. 95-602 has never been implemented. For example:

1. Regulations required by the law six months after enactment have never been finalized to our knowledge;

2. No Secretary's Report has been filed (due Jan 15, '81);

3. All 54 Councils throughout the United States are still controlled by and serving only (with very rare exceptions) the agencies representing the four previously listed conditions (P.L. 94-103);

4. DD literature still lists mental retardation, epilepsy, cerebral palsy and autism as the developmental disabilities;

5. Protection and Advocacy Programs have done nothing, to our knowledge, to aid the lesser known developmental disabilities of which there are many, including Tuberous Sclerosis;

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6. The National Association of Developmental Disabilities Councils (NADDC formerly NCDD) does not represent the true target developmental disability population. None of the Councils (the well from which NADDC exclusive membership of mental retardation, epilepsy, cerebral palsy and autism advocates is drawn) represent the true DD population as defined in P.L. 95-602. (Also described in the Abt Report on the Definition of Developmental Disabilities, Nov., 1977, page 34) For example, it would be a miracle if 10% of the people having epilepsy would qualify for service under the definition of DD in P.L. 95-602.

7. The assessment of .03% of each state's federal allocation for membership to support the NADDC is a flagrant violation of the law.

8. The fourth goal and objective of the NADDC is to lobby for change in developmental disability legislation (see enclosure #1).

9. Conflicts of interest exist within and between developmental disability councils, protection & advocacy groups and the NADDC.

10. The NAADC is a private, federally supported union which represents NARC, EPA, CP and autism. The sole purpose of this agency, in our opinion, is to keep control of and continue to manipulate the DD program for their own special interests. There are many other serious problems at the state, regional and federal levels.

To accept the Waxman bill, H.R. 2943, which is a simple extension of the present developmental disability program at a cost of $60,000,000 is unthinkable to this Association in view of the above. Under Public Law 94-103, 179 million dollars was squandered supporting the four previously listed conditions to the detriment and neglect of countless other developmental disabilities which make up the bulk of the DD population. (Their voices are smaller and scattered, so perhaps you do not hear them. NINCDS does!) While these amounts of money may be small potatoes in the overall budget for HHS, to the average tax paying American citizen, it is a great deal of money which is being misappropriated and mismanaged, to say the least. Since 1973 all that has happened under DD legislation has been in violation of Section 504 of the Rehabilitation Act of 1973.

We strongly recommend no extension of this legislation. In fact, we feel that the developmental disability program is so corrupt and mismanaged that it should be completely scrapped. A second alternative would be to replace all the federal and regional directors. This would include all personnel and staff members who have been a part of the DD program since 1975, and prior thereto (P.L. 94-103). They have all been brainwashed by the agencies representing the four previously listed conditions.

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This is especially applicable to Mr. Francis X. Lynch, Director of the DD program, who gave credence, support and guidance to the NADDC (see enclosure #2), and still condones the .03% assessment of state's allocations to support this illegal and discriminatory agency.

Merge DD with the National Institutes of Health (NIH-NINCDS), Comprehensive Services or the Handicapped. Develop new and firm guidelines under close supervision of Congress and HHS, as recommended by the G.AO. Report. In brief, clean up the mess!

This Association has spent several years collecting correspondence and printed material that will corroborate all the allegations herein stated.

A quick review of the agencies that were privileged to give oral testimony at the recent House and Senate hearings conducted on DD legislation does leave one to wonder, "who is minding the store?" Who speaks for the previously unlisted DDs? Who gives a damn about them?

We ask you to personally respond to the statements made in this letter and relate to us your views and position(s) relevant to the developmental disability program.

Respectfully yours,

Raymond A. Connors

Raymond A. Connors, President
Tuberous Sclerosis Assn. of America

RAC:mm
Encls. (3)

cc: President Ronald Reagan
Vice President George Bush
Thomas P. O'Neill, Jr., The Speaker
Congressman Gerry E. Studds
Subcommittee on Handicapped, Senate Committee on Labor & Human Resources
Senate Committee on Labor & Human Resources
Subcommittee on Health & The Environment, House Committee on Energy & Commerce
TSAA Board of Directors
Phillip A. Terry, Esq.

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STATEMENT BY SENATOR DANIEL K. INOUYE

Before the Subcommittee on the Handicapped of the
Senate Labor and Human Resources Committee

RE: S. 385 -- Rehabilitation Needs of the Pacific Basin

Mr. Chairman:

I am pleased to testify on behalf of my proposal (S. 385) to provide for a study of the many unique and critical health and rehabilitation needs of the Pacific Basin. This legislation, which has evolved from several years of discussion with my cosponsors, Senators Matsunaga and Randolph, will amend Section 202 of the Rehabilitation Act of 1973 by adding a new subsection which directs the National Institute for Handicapped Research to conduct a comprehensive study of the rehabilitation needs of the Pacific Basin, including the need for trained rehabilitation personnel in a region which I believe is essential to our national security. This proposal seeks to initiate a systematic process of long-range planning for the rehabilitation needs of this region so that in ten to fifteen years, individuals will be receiving high quality services appropriate to their needs.

At the end of the 96th Congress during our deliberations on the Continuing Resolution for the Department of Education, House and Senate conferees unanimously agreed that the Department should give high priority to the special needs of

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the Pacific Basin in its plans for long-term initiatives. I can assure you that this proposal has the enthusiastic support of the Governors of the Pacific Basin, who on many occasions, have expressed to me their concerns about handicapped persons within their areas of jurisdiction. In addition, I expect interagency cooperation from the Alcoholism, Drug Abuse, and Mental Health Administration (ADAMHA) of the United States Public Health Service in this proposed comprehensive study.

The Pacific Basin includes American Samoa, Guam, Hawaii, the Commonwealth of the Northern Marianas Islands, and the Trust Territory of the Pacific Islands. These American territories, for which the federal government has special responsibilities to provide health and welfare services, is comprised of over 2,141 islands spread over more than 3.5 million square miles - an area roughly equivalent to the land mass of the continental United States. There are at least 11 local and national governments with complex relationships to the U.S. government. Most of these islands are small and sparsely populated. Communication and transportation facilities range from good in Hawaii to spasmodic and unreliable in the remote Trust Territories. The population of approximately 1.25 million people is composed of many different ethnic groups with diverse cultural and linguistic traditions. As a result of these geographical, social, and cultural characteristics, logistical problems in the delivery of health and

rehabilitation services pose a special challenge to traditional patterns of service delivery.

A study of the rehabilitation problems of the Pacific Basin is, in my judgment, long overdue. Unless one has actually had the opportunity to visit the Pacific Region, the lack of some of the most rudimentary health care components is simply incomprehensible. To state perhaps the obvious, the level of health care in a society affects the overall quality of life for all citizens and an individual's aspirations for the future. Yet, available estimates of health problems of this area only begin to suggest some of the critical problems faced by individuals living in the Pacific Basin. Hearing disorders are rampant. Many of the Pacific Islands of the Trust Territory and on Guam harbor serious local diseases of viral nature which attack the central nervous system and affect hearing, eventually leading, to paralysis and death. Serious middle ear infections are an almost foregone conclusion for many inhabitants of the islands. The resultant transient and permanent losses of hearing are virtually unattended.

In the Marshall Islands, nearly half of those 50 or over have diabetes. The incidence of childhood leukemia in Ponapae and Kosrae is 10 times the expected rate. Incidence of high blood pressure in Guam and the Northern Marianas is 35 percent for those over 30 years of age. Major alcoholism and drug abuse problems continue unchecked. Adolescent

suicide rates are among the highest in the world. Tuberculosis remains a serious health problem for both children and adults.

The meaning of these numerically based descriptions when translated into human terms is particularly poignant. To be a handicapped person in the Pacific Basin is to experience "triple threat" - for not only is an individual handicapped, but he or she is likely to be poor, unemployed or underemployed, and a member of an ethnic group for which rehabilitation services now existing may not be appropriate.

The need for trained rehabilitation personnel, facilities, and appropriate delivery systems in the Pacific Basin cannot be overstated. All are nonexistent. Furthermore, there is a complete absence of ongoing training programs to rectify this critical situation. In all of the Trust Territories, there is only one registered physical therapist, 14 expatriate physicians, and 36 Fiji-trained medical officers, all of whom are in their mid-fifties with no new ones in the training pipeline. The Pacific Region is plagued by the lack of employment opportunities for its residents. Most of the young and middle-aged migrate to Hawaii and the continental United States, leaving a population of the very young and old. Here is an unprecedented opportunity to train native professionals and paraprofessionals to serve some basic health needs of their region.

A comprehensive study would provide much needed information for future planning and long-term program development in the

Pacific Basin. Such a study is relevant to several expressed National Institute for Handicapped Research priority areas, including the rehabilitation of handicapped individuals living in underserved, rural areas, the development of service delivery systems for multicultural and multilingual populations, and demographic studies of rehabilitation needs. It is my understanding that although service to minority populations is a priority of the National Institute for Handicapped Research, only 0.4% of its funds are currently spent in this area.

Senators Matsunaga and Randolph have joined me in cosponsoring this bill. I respectfully request that prompt and favorable attention be given to this critical measure by your Subcommittee.

STATEMENT BY DR. TERENCE ROGERS
DEAN, SCHOOL OF MEDICINE
UNIVERSITY OF HAWAII

Before the Subcommittee on the Handicapped of the
Senate Labor and Human Resources Committee

RE: S. 385 -- Rehabilitation Needs of the Pacific Basin

Mr. Chairman:

The American parts of the Pacific Ocean include my home state -- Hawaii; Guam, American Samoa, the Trust Territory of the Pacific Islands -- also known as Micronesia; and a few other strategic knobs. Guam is formally a Territory and is a fairly developed place. American Samoa is certainly not highly developed but has the advantage of being relatively compact. The substance of my testimony today applies to both American Samoa and Micronesia.

The Trust Territory of the Pacific Islands is an almost forgotten responsibility of the United States. It covers an area equal to that of the continental United States, but is made up of thousands of islands separated by empty stretches of open ocean. These islands were once German colonies taken over by Japan at the outbreak of the 1914 War and afterwards retained by Japan under a League of Nations mandate. They were captured by U.S. military forces during World War II or surrendered at the end of the war. Kwajalein and Saipan were headline-familiar in World War II and, for different reasons, Bikini and Eniwetok became so later.

The U.S. has governed these islands since World War II under a United Nations Strategic Trust which is due to terminate in 1982. After that time, however, the U.S. will retain responsibility for health, education and other funding in the new political entities for a further fifteen years.

For many disputed reasons, the quality of life in the Trust Territory more resembles that of the so-called Third World than a U.S. territory, except that eligibility for Food Stamp and Commodity Programs has eliminated the problem of starvation. Great efforts on the part of the TTPI government and special programs funded by DHHS have brought primary health care and hospitalization to the somewhat urbanized District Centers, but the outer islands remain seriously under-served. Basic sanitary engineering is very deficient, with most residents having no access to safe running water and no sewage disposal system. Consequently, intestinal parasites and water-borne diseases are endemic.

In this kind of environment it is not surprising that rehabilitation facilities are almost completely lacking. For example, there is just <u>one</u> physiotherapist on the Island of Majuro in the Marshall Islands, and no others. We wish to bring the attention of the Committee to this problem and to propose the development of a systematic and far-reaching <u>plan</u>. We do not wish to propose some short-term funding for short-term demonstration projects which are doomed to

failure because the fiscal and physical realities of Micronesia cannot support them. In the primary health areas, too many programs have died because they were designed for the relatively affluent and mobile United States poor.

In addition to the fact that the U.S. did indeed take the responsibility for these islands it is clearly in our national interest to encourage stable and secure societies. The strategic importance of this area is often overlooked simply because no other great power has shown any overt moves. The forthcoming independence of some entities may well change the picture.

We now wish to propose the development of a plan for services to the handicapped which will improve the quality of life in Micronesia and, at the same time, be a plan which will fit the realities of Micronesia through the end of this century. This would be, in effect, an agreement which would delineate in advance the progress and expectations on the part of the Micronesian peoples and the U.S. Government. A mutually respected plan can lead to steady progress rather than the usual sprinkling of good intentions where they are not needed or are inappropriate.

We are here to advance the importance of <u>developing</u> such a program; we do not have one ready-made; the issues are too complex.

Any plan will have to take into account the realities of

the client population (which are not known at this time) and the environmental realities, the distances, the lack of support services and the nature of family structures. It will also have to be tailored to the resources of the U.S. and the Micronesian government entities will be able to apply to rehabilitation and other services to the handicapped.

A realistic program will require the development of completely different approaches in many areas where we have made great strides in a highly organized and technology oriented society. The phrase "appropriate technology" will need to become alive to meet the needs. We will need to address the training of rehabilitation personnel, for example, among an intelligent but marginally educated population.

The basis of any plan must be the needs as perceived by the health leadership in Micronesia, but the details will require a great deal of experienced input. We emphasize again that programs from the continental U.S.A. cannot be simply superimposed in the different environments and cultures of the central Pacific. Dr. Eliuel Pretrick, now Health Director for the Federated States of Micronesia, once said, "Many of the nice things that happen to us do not work out very well." Among many other talents, he is noted for his politeness.

In the 22 years since Statehood, Hawaii has come a long way in almost every respect, and especially in institution

building. The Health Science Schools of the University of Hawaii have entered into partnership with their colleagues in the Trust Territory and the USPHS to develop some programs of lasting value in primary health care. The Rehabilitation Hospital of the Pacific has also been active in outreach programs in the American Pacific. Now this hospital and the University of Hawaii Schools of Medicine, Public Health, Nursing and Social Work have the necessary experience and, therefore, the humility to approach this proposed planning with open eyes and open minds, and in full partnership with the Health Departments of the emerging Micronesian political entities.

STATEMENT BY MR. PATRICK DUARTE
ADMINISTRATOR AND CHIEF EXECUTIVE OFFICER
REHABILITATION HOSPITAL OF THE PACIFIC

Before the Subcommittee on the Handicapped of the
Senate Labor and Human Resources Committee

RE: S. 385 -- Rehabilitation Needs of the Pacific Basin

Mr. Chairman:

My name is Patrick Duarte, Administrator and Chief Executive Officer of the Rehabilitation Hospital of the Pacific located in Honolulu, Hawaii. I am speaking on behalf of the Board of Directors of the hospital in support of S. 385, the "Pacific Basin Rehabilitation Needs Study Act."

The Rehabilitation Hospital of the Pacific is a 100-bed, free-standing, non-profit, specialty hospital dedicated to serving the disabled population of Hawaii and the Pacific Basin. We are the only rehabilitation facility in the entire Pacific area to be fully accredited by both the Joint Commission on Accreditation of Hospitals (JCAH) and the Commission on the Accreditation of Rehabilitation Facilities (CARF). We are the only hospital in the State of Hawaii with a comprehensive physical restoration program.

The hospital's formal mission statement commits the hospital to provide on-going services to the people of the Pacific Basin. To this end, a master plan has been developed which includes outreach programs and personnel training pro-

grams specifically aimed at addressing the needs of the Pacific Basin. Through the generosity of the Federal Government we have been able to construct the facilities required to support our master plan, and we have made some progress in establishing programs dealing with the Pacific Basin. However, we have found that properly serving American Samoa, Guam, the Northern Mariana Islands, and the Trust Territory of the Pacific is an extremely complex undertaking. Our traditional treatment techniques are not applicable due to cultural and environmental differences, and because of the tremendous distances involved.

The objective of rehabilitation is to return the patient to independent living in his own community. Patient treatment programs must therefore be customized to each individual's home and community setting. Needless to say, it has not been feasible for our social workers and therapists to make site investigations of home conditions 3,000 miles away, nor is it possible for them to draw generalized conclusions about environmental conditions in this multi-cultural and geographically dispersed region. Consequently, substantial sums of money may be spent on training a patient in a completely inappropriate activity. For instance, a basic element of our treatment protocol is tub and shower training. In many of these cultures, western style bathroom facilities are non-existent. Another situation which is quite common is prescribing

equipment and adaptive devices, such as wheelchairs, for people who will go back to a world with no sidewalks or accessible buildings. We have run into numerous problems because we cannot practically evaluate the home environment.

Language differences, distance, poor communication systems, unfamiliar social norms and political factors have all contributed to the horrendous problem of communicating with the people of the Pacific Basin. Coordination of patient referrals to our hospital has been inadequate to say the least. However, of even greater concern is what happens after discharge. Our normal procedure is to see our patients on an outpatient basis to ensure adequate follow up and to reinforce what was learned during their inpatient stay. Follow up by our hospital is virtually impossible when a patient from the Pacific Basin returns home. Furthermore, because of the shortage of trained personnel and the dispersion of the islands, continuity of care cannot usually be provided.

In short, our past experience has demonstrated a definite need to improve the rehabilitative services throughout the Pacific area. Whatever is done must be well thought out and responsive to their diverse and very unique requirements. A long term plan should be developed through the concerted effort of the numerous professional disciplines involved in rehabilitation. Successful implementation of the plan will be dependent upon a dedicated staff of professionals and the

organizational support of a well-established institution.

The Rehabilitation Hospital of the Pacific, in partnership with the John A. Burns School of Medicine of the University of Hawaii, is eager to support the development and implementation of a master plan for the Pacific region. Our hospital, in cooperation with the University, can offer the necessary combination of research, training and clinical expertise to accomplish the task at hand. We share a very deep concern for the welfare of the inhabitants of the Pacific Islands and we have a common mission to serve our distant neighbors. While we are ready and willing, our financial resources are insufficient to appropriately plan and implement the necessary programs. The proposed bill will certainly provide for the studies and planning needed, and we therefore support it without reservation. We can be counted on for any needed assistance; however, our involvement is of secondary importance to the need for comprehensive assessment of the Pacific Basin and the establishment of a workable plan for the rehabilitation of disabled people in this area.

STATEMENT BY MR. EPEL K. ILON
ASSISTANT LIAISON OFFICE, WASHINGTON OFFICE
THE FEDERATED STATES OF MICRONESIA

Before the Subcommittee on the Handicapped of the
Senate Labor and Human Resources Committee

RE: S. 385 -- Rehabilitation Needs of the Pacific Basin

Mr. Chairman:

My government, the Federated States of Micronesia, supports S. 385, and welcomes this opportunity to comment on it.

As much as we would like to see a comprehensive plan developed for the Federated States of Micronesia, we would hope that such plan be implemented on a timely fashion and the need to do just that can be reflected in the testimony on S. 385. In addition to the need for a timely implementation of the plan, the transitional status of the Trust Territory of the Pacific Islands should be considered so that the study does not run into undue delay and red tape. Relative to this latter concern, we would recommend that Section 3 (j) (2) of the bill that, in the case of the Trust Territory, consultation should be with the "chief executives" of the emerging governments of the Federated States of Micronesia, the Republic of Palau and the Marshall Islands, who shall consult with the High Commissioner in so far as it pertains to his role to be consulted in federal programs.

We hope these two concerns of the Federated States of Micronesia can be incorporated into the records of the hearing and that any actions subsequent to the hearing take into account our two concerns.

Testimony of
AMERICAN SAMOA GOVERNMENT

on Senate Bill 385
PACIFIC BASIN REHABILITATION NEEDS STUDY

American Samoa supports the passage of S.B. 385 - Pacific Basin Rehabilitation Needs Study Bill. This bill supports local efforts to assess local endeavors to curb increasing health problems impacting the local population. In the absence of accurate data, meaningful programs cannot be formulated. The proposed study should provide the necessary information to allow proper development of programs.

In the American Samoa Plan For Health, the following long-range goals have been established for the Territory:

- .Attain an acceptable level of the occurence of hadicapping conditions in the Territory and restore handicapped individuals to their fullest physical and mental capacity
- .To provide, directly or through arrangement with off-island institutions, appropriate rehabilitation and restorative services necessary to assist impaired individuals to maintain, or regain, their fullest possible physical, mental, social and economic capabilities
- .The elderly and others suffering from physical or mental disabilities should have access to a full range of medical and social services including home health care, homemaker services, day care and other services appropriate to their needs while living in the Territory.

These general goals represent the aspirations of the American Samoa people, however, the magnitude and the level at which these services can and should be provided can only be assessed after data and relevent information has been collected. This study will therefore be welcomed.

A few examples of the problem areas follow to demonstrate the need

for the proposed study.

Handicapping Conditions. This area of concern focuses on individuals whose physical and mental functioning has been temporarily or permanently impaired as a result of an aquired action or whose potential for functioning on a level with his/her peers is significantly lessened through a generic or developmental deficiency.

Many handicapping conditions are the result of diseases or incidents which can be prevented or minimized through changes in individual behavior and/or health services.

The rate of which handicapping conditions resulting from accidental or intentional trauma conditions, is also related to actions by programs and agencies which lie outside the health field, such as environmental and occupational programs, public safety programs and services and other regulatory programs.

An analysis of hospital discharges for CY 1972-73 shows that an average of about 30 people per year suffer a major stroke in American Samoa. Of this number, approximately 63 percent die from the incident. Of the surviving number, approximately 82 percent suffer from paralysis in American Samoa annually.

Mental Health System. There is no territorial "mental health system" in the true sense of the term. There is, rather, an array of government services and private sources of care that may be loosely tied by verbal or written cooperative agreements.

All institutional mental health services are provided through the mental health program of the Territory's Department of Health.

Suicide. Since 1969, the average annual rate of suicides has been about 9 per 100,000, which compares favorably with the 1975 U.S. rate. However, a high percentage of the suicides occured among the 15-34 age group.

Alcoholism and Alcohol Abuse. Although there is virtually no hard data in American Samoa on the incidence of alcohol abuse and alcoholism, there are several surrogate measures that indicate that the problem is a significant one in the Territory.

A 1974 survey of high school seniors indicated that 20 percent had used alcohol. The average initial drinking experience occurred at age 16.3 years for boys and 15.9 years for girls. School officials estimate that over 70 percent of the high school students use alcohol. In 1976, 85 percent of the traffic fatalities were alcohol related. American Samoa has the third highest alcohol consumption rate per capita in the world.

These few examples of problem areas are indicative of the need for the proposed study. The results of the study will assist both the Federal and local governments determine the resources which need to be allocated for new programs and services. American Samoa would welcome the study assistance and, therefore, supports Senate Bill 385. Fa'afetai.

Commonwealth of the Northern Mariana Islands
Office of the Governor
Saipan, Mariana Islands 96950

Cable Address:
Gov. NMI Saipan

APR 10 1981

APR 20 AM 11:10

The Honorable Daniel K. Inouye
United States Senator
Room 105, Russell Senate Bldg.
Washington, D.C. 20510

Dear Senator Inouye:

In response to your letter of February 12, 1981, I am happy to provide written testimony on the proposal for a study of Mental Health, Rehabilitation, and Manpower needs in the Pacific Basin. We are grateful for your support and assistance to the Commonwealth of the Northern Mariana Islands.

TESTIMONY ON SENATE BILL 385: A BILL TO AMEND THE REHABILITATION ACT OF 1973 TO PROVIDE FOR COMPREHENSIVE STUDY OF THE REHABILITATION NEEDS OF THE PACIFIC BASIN

A Mental Health and Substance Abuse plan of services is being developed in the Commonwealth of the Northern Mariana Islands at this time. The plan development process has uncovered a number of specific mental health needs, based on the previous utilization data available; however, the process has also uncovered the serious lack of dependable data that could be used to predict prevalence and incidence of mental illness in the general population, or identify target groups at high risk of developing mental, behavioral, or psychological problems.

Most of the area studies that are available are either quite dated or have been specifically focused on a limited concern, such as juvenile delinquency or child abuse. There have been a very few informal studies of alcohol and drug abuse prevalence among high school students, but no investigation as to the correlates of abuse. Also, there is almost no data available on the prevalence of substance abuse among adults, though the general opinion is that it is very prevalent.

Using treated prevalence rates as an indicator of the general need for mental health services is apt to seriously underestimate the actual potential need for mental health services. Because of the problems of community acceptance of mental health services, and the problems in the health referral and record keeping systems, the figures are difficult to interpret. At any rate, the interpretations must be made cautiously and conservatively, as will be explained after the presentation of the two sets of data following. One set of figures is taken from the records of the outpatient departments on Saipan and Rota for the three-year-period between 1975-1977. The second set of figures is taken from the records of the Division of Mental Health inactive patient file for the five-year-period between 1974-1978.

FIGURE 1

COMPARISON OF PREVALANCE RATES: MENTAL DISORDERS DIAGNOSES VS. MH INACTIVE FILES

(Population figure for the period = 14,000; case number totals based on 3 and 5 years; rates per thousand based on one year, or divided by 3 or 5.)

	MENTAL DISORDERS DIAGNOSES		MH INACTIVE FILE	
	# Cases 1975-77	Rate per 1000 per year	# Cases 1974-78	Rate per 1000 per year
SOMATIC	139	3.31	31	.44
DRUG/ALCOHOL	33	.78	12	.17
PSYCHOSIS	27	.64	22	.31
BEHAVE/ADJUST	6	.14	26	.37
FAMILY/MARITAL			26	.37
CHILD ABUSE			12	.17
SUICIDE			9	.12
DEPRESSION			2	.02
MR			28	.40
PSYCHOLOGICAL EXAM FOR MR - NEGATIVE			14	.20
NEUROLOGICAL			34	.48
				1.08

Discussion

The Mental Health files did not have the fine-grained diagnostic categories available on the disease summary cards, so the Mental Disorder categories were collapsed to match the MH diagnoses. The much lower rate per thousand for Department of Mental Health probably reflects the unwillingness of patients to receive MH services, whereas they are willing to go to the outpatient hospital physician with a "physical" complaint. Patients with psychosomatic illnesses typically resist psychological treatment, in any case. These data suggest that the psychosomatic target group of patients should be approached indirectly, possibly through a specially trained outpatient nurse. (Or possibly, some training could be given to general hospital staff on how to best manage these cases.)

...ral Source Analysis

From this sample it appears that Division of Mental Health is receiving a relatively large number of incorrect referrals, especially in the neurological category. Again, it suggests a training program for general hospital and MH staff to more accurately detect those somatic symptoms which are responsive to psychological treatment.

From some points of view it could be considered that the large volume of psychological testing requested for cases of suspected Mental Retardation (MR) is an inappropriate referral. There are advantages to maintaining this however, not the least of which is the possibility of receiving payment for the test batteries given for such agencies as Social Security Disability Insurance. It also provides training opportunities for the local MH staff and solidifies inter-agency relationships with the Division of Mental Health. If, on the other hand, the referral load became too time-consuming, this is a category of client that could be transferred to the care of the Division of Special Education or Vocational Rehabilitation. An analysis of all referral sources reveals that each problem type is usually favored by one or two referral sources.

DIAGNOSIS	REFERRAL SOURCE	% OF ALL REFERRALS
Somatic	hospital staff	29%
Learning Disability	schools/SSI	20%
Misconduct	schools/court	14%
Psychosis Suicide Child Abuse Drug/Alcohol	hospital OPD/police	22%
Family/Marital	self referred	12%
Depression	self referred	3%
		100%

This breakdown makes the fact altogether clear that Division of Mental Health receives referral predominately of those cases who are bothersome to others, excepting the somatic and self referrals, of course. Most likely Division of Mental Health is viewed by the community as an intermediate step in the criminal justice system, an extension of the "long arm of the law". It is not to the benefit of the client to have to become socially disruptive before receiving help, however. This conflict suggests that if mental health were less stigmatized and stigmatizing, perhaps some of these cases would refer themselves, or at the least, not feel as resistive to treatment. The argument moves toward establishing at least a partial Mental Health treatment base away from the hospital and its population of chronic psychiatric patients. An optimal division, based on the referral source percentages above, would look like this:

Hospital treatment	Somatic	29%	Community-based treatment	Learning Disability	20%
	Psychosis			Misconduct	14%
	Suicide			Fam/Marital	12%
	Child Abuse	22%		Depression	3%
	Drug/Alcohol				49%
		51%			

The affect of widening the treatment base would be a greater case-finding affect which would serve an outreach function. Just the case-finding affect of hiring a full-time psychologist on staff increased the number of clients to 84 new referrals the first year compared to a total of 227 clients over the period of the previous five years. This represented a 111% increase in referrals, a 98% increase in clients. Such increases may be explainable on the basis of increased population, as well. Still, there is a hint that a little outreach might go a long way in encouraging people to take the first step to get help if needed.

Ethnic Representation in Division of Mental Health Referrals (years 1974-78)

In order to test whether referrals to Division of Mental Health are representative of the population, a second referral grouping was made. A breakdown of referrals from the Division of Mental Health inactive file survey shows:

Chamorro	67%	151
American	12%	27
Carolinian	10%	23
Trust Territory Pacific	6%	14
Other	5%	12

A Trust Territory psychologist was responsible for the Division during these years and probably attracted referrals from Trust Territory employees, partially accounting for Americans being the second largest group represented.

An ethnic grouping was made for active cases referred during the last two years (DMH years 1979-80), while there was a Commonwealth based psychologist responsible for the Division. The categories changed like this:

Chamorro	53%
Carolinian	23%
American	14%
Trust Territory Pacific	7%
Other	3%

is, of course, impossible to be sure of the reasons for the change of representation of Carolinians in the sample, they more than doubled their proportion. It is possible to suspect that it was partly due to the hiring of a former Carolinian patient as a part-time MH patient care worker and translator. The obvious recommendation stemming from this experience is to ensure that a Carolinian MH worker is at all times available for this program.

Otherwise, the ethnic referral pattern does not confirm the suspicion that "only Americans come to therapy". It shows a fairly representative cross-section of the predominant ethnic types in the population. Conspicuously absent are only third world nationals, or alien workers, and the Japanese tourists.

Longitudinal Comparison of Referrals for Mental Health Treatment

The data just presented indicates that there has been a continuing need for mental health rehabilitation and treatment over a period of years; but is that need increasing or decreasing? This question too, is difficult to answer, given the scarcity of available data; however, in order to make whatever comparisons are possible, the patient data from the inactive files of the Division of Mental Health were compared to the appointment log data for the past two year period between 1979-80, Figure 2 refers:

Figure 2

COMPARISON OF PREVALENCE RATES: DMH YEARS 1974-78 and DMH Year 1979-80

(Population figure for Year 1979-80 = 16,600; 100 subtracted for Northern Island population since none were served. Ages under 15 included in both samples of DMH cases since youth are represented in case load.)

	DMH YEAR 1979-80		DMH YEARS 1974-78	
	# Cases	Rate/1000	# Cases	Rate/1000
SOMATIC	7	.42	31	.44
DRUG/ALCOHOL	6	.36	12	.17
PSYCHOSIS - TOTAL	26	1.56	22	.31
Chronic	11	.66		
Acute	15	.90		
BEHAV/ADJUST - TOTAL	25	1.50	26	.37
Adult	19	1.14		
Youth	6	.36		
CRIMINAL JUSTICE REFERRALS TOTAL	8	.48		
Adult	3	.18		
Youth	5	.30		
DEPRESSION	1	.06	2	.02
MR	11	.66	28	.40
MR - TOTAL			42	.60

Discussion

The obvious contrast in the two samples is the striking increase in psychosis and behavioral adjustment disorders. The behavioral adjustment cases were almost exclusively self referred during 1979-80, reflecting a possible growing acceptance of MH treatment, at least for certain people. The psychosis referrals may be due to the case finding effect of having a full-time psychologist on board, but this explanation seems too simple, especially considering the severity of the symptoms, and the scant probability that these clients would be monitoring staff availability. The jump in referrals could just as well represent the greater willingness on the part of families to hand such a patient over to the government rather than to continue struggling privately. If so, this referral category increase could reflect on the weakening of family and community bonds. The increase could also be a measure of the increased stress of living in terms of greater population, greater economic distress, increased emmigration and immigration, and resulting instability.

Referral Source Analysis

Changes in referral source pattern from one sample to the other most probably reflects the personal preferences of the two psychologists involved since the development of referral contacts is a very individual endeavor. Referral source groupings for the Year 1979-80 follow:

REFERRAL SOURCE	1979-80 PERCENTAGE	1974-78 COMPARISON
Hospital	23%	51%
Criminal Justice	19%	
Individual, Self Referred	19%	3%
Family, Self Referred	14%	12%
SSI	7%	20% (?)
Clergy, Youth/School	6%	
School	4%	14% (?)
PHS (Public Health)	4%	
VR Voc. Rehabilitation	2%	
Other	2%	
	100%	

Since referral sources were recorded differently in the two samples, a complete comparison cannot be made. In the 1974-78 sample, referral combinations are recorded, such as school, SSI, and can't be interpreted. Of the sources which can be interpreted, individual self referrals increased 500% - a further testimony to the possible growth of acceptance of MH services. A second clear-cut difference is the decrease in hospital referral percentage from half of all referrals to less than one quarter. This again may be the difference in having a full-time staff who would make more community contacts.

Conclusion

Hopefully, it is clear from this testimony that there is some indication of a need for mental health services in the Commonwealth. The more obvious conclusion is that there is a need for a complete and dependable survey of mental health needs within the community, not just at the hospital. The accurate definition of mental health treatment and rehabilitation needs is crucial at this time because the Commonwealth is faced with the decision of whether to fund the mental health program from local Covenant funds. For the past two years federal funds which previously supported the program have not been available. For Fiscal Year 1982 there has not been any money appropriated by the Commonwealth Legislature to continue the services of a qualified psychologist or a full-time chief for the division. Solid data on the need for these positions would be invaluable in evaluating such a decision for future years.

As a final statement I would like to repeat the recommendations made in my letter of February 3, 1981. Although the Commonwealth fully supports the effort at identifying specific needs for mental health treatment and rehabilitation, there are certain conditions we would like to see imposed. As previously stated, we would like to suggest that a block grant mechanism be proposed, similar to the guidelines set up by the consolidation of grants to the insular areas, 42 CFR, Part 50, effective December 12, 1979. Under this condition each political entity would be eligible for a block grant funded jointly by the Departments of Education and Health and Human Services, including the Institute for Handicapped Research; Alcohol, Drug Abuse, and Mental Health Administration, Bureau of Health Manpower. A proportion of the funding could come from each agency.

In this way, each block grant recipient could contract to have one comprehensive needs assessment study done covering all three fields of rehabilitation - substance abuse, mental health, and manpower needs. Local departments of each political entity of the Pacific could apply for funds through either the education or the health departments. It is important that the local entity have the flexibility to contract for the study according to local definitions of what is needed.

We are grateful that you are putting forth this effort to assist the Commonwealth of the Northern Mariana Islands and the other Micronesian states in their development toward self-sufficiency. We especially appreciate your advocacy on our behalf. We sincerely hope that we can continue to count on the State of Hawaii as a continuing resource for all the Pacific states and nations.

Hafa Adai,

CARLOS S. CAMACHO
Governor

PAUL M. CALVO
Governor

Territory of Guam
Office of the Governor
Agana, Guam 96910
U.S.A.

TESTIMONY
S.385

To: The Subcommittee on the Handicapped of the Senate
Labor and Human Resources Committee

Honorable members of the Subcommittee on the Handicapped, I am pleased to offer testimony, on behalf of the people of Guam, concerning Senate Bill 385. The "Pacific Basin Rehabilitation Needs Study Act", as submitted by Senators Inouye, Matsunga and Randolph, certainly meets with our wholehearted support and commitment. The health and social welfare needs of the inhabitants of the Pacific region are indeed unique. Whether one views the area collectively or as individual entities each with varied needs, a comprehensive study concerning the rehabilitation requirements of the Pacific Basin would be most beneficial in providing direction for future development.

To be effective each area must be focused upon separately. The needs of Guam are vastly different for other Pacific Basin members. Individuals unfamiliar with this area are often surprised to find that those conditions which are commonly accepted as having a very low per capita incidence rate are in fact prevalent among our people. Why do these diseases affect us more than other we do to understand and provide effective treatment? Guam, for example, has the highest per capita incidence rate of Amyotrophic Lateral Sclerosis (A.L.S.) Guam also experiences a particular type of Parkinson's disease, known as Parkinson's Dementia, which is not found anywhere else in the world. Otitus Media, a condition affecting the middle ear, which is easily treated elsewhere, often is very difficult to treat on Guam. This condition is one of the causes of a higher incidence of hearing impairments on Guam than that found in other areas.

It is of critical importance to the people of Guam, that the larger scientific and health related communities join together with the people of the Pacific to understand the unique cultural and environmental factors which undoubtedly create these conditions. Standard medical and rehabilitation practices simply will not provide adequate answers to the problems presented in this region.

With these concerns in mind, I ask that Senate Bill 385 receive favorable consideration. The people of Guam stand ready and willing to support the implementation of this study. We wish to thank the sponsors of this bill for their concern and vision in this matter. Surely, the people of Guam and greater the Pacific Region will benefit greatly from the greater outcome.

Respectfully Submitted:

PAUL M. CALVO

STATEMENT ON S. 385 PROVIDING FOR A STUDY OF THE
REHABILITATION NEEDS OF THE PACIFIC BASIN
BY SPARK M. MATSUNAGA
A SENATOR FROM HAWAII
LABOR & HUMAN RESOURCES COMMITTEE
SUBCOMMITTEE ON THE HANDICAPPED
Thursday, May 7, 1981

Mr. Chairman, I am pleased to have the opportunity to testify today in support of S. 385, legislation to provide for a comprehensive study of the rehabilitation needs of the Pacific basin. This measure, of which I am a cosponsor, would amend Section 202 of the Rehabilitation Act of 1973 by specifically directing the National Institute for Handicapped Research to conduct a study of this vital region with particular attention to the pressing need for providing this area with a sufficient number of trained and competent medical personnel.

Such a study is long overdue and is, in fact, consistent with the long term objectives of the National Institute for Handicapped Research. For the Institute has expressly cited the rehabilitation needs of the Pacific basin as deserving of specific assistance. This region, which includes American Samoa, Guam, Hawaii, the Commonwealth of the Northern Marianas Islands and the Trust Territory of the Pacific Islands, comprises over 2,141 islands and encompasses over 3.5 million square miles--an area equal in size to the continental United States. The home to over 1.25 million people of diverse ethnic, cultural and linguistic backgrounds, the greater part of this region has been the special responsibility of the United States as a strategic trust under the United Nations since the end of the Second World War. In much of the American Trust Territories, however, the quality of life approximates the living standards that are more often associated with the Third World, especially with regard to primary and preventive health care. This fact is not only unfortunate, but potentially dangerous to the security of our Nation.

The strategic importance of our continued presence in this area is self evident. The United states has always placed a high priority on being a major sea power and the Pacific has long played a pivotal, yes essential, role in enhancing our national interest. Growing foreign influence in the Pacific Trust Territories could very well reek havoc with the string of American bases that have been established in this area. It is not entirely unimaginable that instability in the Trust Territories could threaten, as well, the security of Guam and Hawaii.

It is paramount, therefore, that we strive to create and maintain a society in these territories that is both confident enough in itself and stable enough in its structure not to fall

prey to foreign exploitation. That is why we have a special duty to provide the Pacific basin with adequate health and welfare services. We need to know that the level of health care in a society affects its overall quality of life, and determines as well, that culture's future aspirations.

Some jurisdictions in the Pacific basin are regrettably deficient in their ability to provide for public health and health care delivery. They regularly experience periodic epidemics, and unacceptably high incidences of hepatitis and tuberculosis, in addition to an array of enteric diseases, including typhoid fever. On some of the islands, intestinal infections and parasites are so common among children that many parents have come to regard them as normal.

In the Marshall Islands, nearly half of the individuals, aged fifty years and older have diabetes. The incidence of high blood pressure in Guam and the Northern Mariana Islands is 35% of the individuals over thirty years of age, and the incidence of childhood leukemia on Ponape and Kosrae is ten times the expected rate. There are major drug abuse and alcoholism problems as well, and in the Trust Territory suicide is the primary cause of death for adolescents at a rate for that age group which is the highest in the world. In addition, leprosy, yaws, and filariasis are still prevalent and remain a serious threat to children throughout the Pacific basin.

Compounding the seriousness of these conditions is the extreme lack of qualified rehabilitation and health personnel, and the total absence of ongoing training programs to help alleviate this situation.

The dire need for trained rehabilitation personnel in the Pacific basin cannot be overstated. In all of the Trust Territories, there is only one registered physical therapist, 14 expatriate physicians, and 36 Fiji-trained medical officers. This situation presents an unprecedented opportunity to train native professionals and paraprofessionals to service some of the basic needs of their own people.

A comprehensive study such as this legislation calls for would provide the much needed information for the planning and long term program development that is so essential for the future of the Pacific basin and the well being of its residents. The sorry state of the health care delivery system in the Trust Territories must be turned around. The health of that area's population demands it, and our own national security interests require it. The stakes are just too high for all involved to do otherwise.

Accordingly, I respectfully urge the members of the subcommittee to expeditiously give every favorable consideration to this vital measure.

Thank you.

COMMITTEE ON
WAYS AND MEANS
SUBCOMMITTEES:
HEALTH
OVERSIGHT

Congress of the United States
House of Representatives
Washington, D.C. 20515

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May 12, 1981

Chairman Lowell P. Weicker, Jr.
Subcommittee on the Handicapped
Committee on Labor and Human Resources
10-B Russell Senate Office Building

Dear Mr. Chairman:

I would like to take this opportunity to commend Senator Inouye on his leadership in the area of Pacific Basin development and to express my support of his bill, S.385, which would amend the Rehabilitation Act of 1973 to provide for a comprehensive study of the rehabilitation needs of the Pacific Basin.

There is overwhelming evidence which supports the need to examine the health problems of the residents of the Pacific Basin. Statistically, these people rank well below levels we generally consider to be acceptable in terms of the numbers of people afflicted with infectious diseases and problems such as high blood pressure, drug abuse and alcoholism. The dearth of available, qualified health personnel to assist in rehabilitation and training programs makes further evident the fact that little progress is being made in addressing the needs of the Pacific Islanders.

In providing for a study of the rehabilitation needs of the people of the Pacific Basin, S. 385 will serve as the impetus for further planning, which will hopefully lead to the ultimate development of a national strategy in providing for the health care of these people.

Mr. Chairman, in view of our government's historic commitment to socio-economic progress, I believe we have an obligation to provide the people of the Pacific Islands with the services and technology that the rest of us in American society have come to enjoy. This measure will give these people a chance to pursue a more promising way of life, and I hope the Committee will judge favorably this legislation to provide a measure of hope to these people.

With warm aloha,

Cec Heftel
Member of Congress

CH:lm

Senator WEICKER. I want to thank all of those who have testified for the input which you have given to the committee relative to the act itself and for your observations on that which is proposed by the administration for the administration of the act. I can assure you that this committee will do its own thinking, and come forth, with its work product, and that product will very much be based on what it is that we have heard here this morning.

Thank you all. The committee will stand in recess.

[Whereupon, at 12:50 p.m., the subcommittee was adjourned.]

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